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# Person- and Family-Centred Care



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# Person- and Family-Centred Care

## Greetings from Doris Grinspun, Chief Executive Officer, Registered Nurses' Association of Ontario



The Registered Nurses' Association of Ontario (RNAO) is delighted to present the clinical best practice guideline *Person- and Family-Centred Care*. Evidence-based practice supports the excellence in service that health professionals are committed to delivering every day. RNAO is delighted to provide this key resource.

We offer our heartfelt thanks to the many stakeholders who are making our vision for best practice guidelines a reality, starting with the Government of Ontario, for recognizing RNAO's ability to lead the program and for providing multi-year funding. For their invaluable expertise and leadership, I wish to thank Dr. Irmajean Bajnok, Director of the RNAO International Affairs and Best Practice Guidelines Centre, and Dr. Monique Lloyd, the Associate Director. I also want to thank the co-chairs of the expert panel, Eleanor Rivoire (Executive Vice President and Chief Nursing Executive,

Kingston General Hospital [2003-2014]) and Sholom Glouberman (President, Patients Canada) for their exquisite expertise and stewardship of this Guideline. Thanks also to RNAO staff Brenda Dusek, Andrea Stubbs, Anastasia Harripaul, Tanvi Sharma, and the rest of the RNAO Best Practice Guidelines program team for their intense work in the production of this new Guideline. Special thanks to the members of the expert panel for generously providing time and expertise to deliver a rigorous and robust clinical resource. We couldn't have done it without you!

Successful uptake of best practice guidelines requires a concerted effort from educators, clinicians, employers, policy-makers, and researchers. The nursing and health-care community, with their unwavering commitment and passion for excellence in patient care, have provided the expertise and countless hours of volunteer work essential to the development and revision of each best practice guideline. Employers have responded enthusiastically by nominating best practice champions, implementing guidelines, and evaluating their impact on patients and organizations. Governments at home and abroad have joined in this journey. Together, we are building a culture of evidence-based practice.

We invite you to share this Guideline with your colleagues from other professions and with the patient advisors who are partnering within organizations, because we have so much to learn from one another. Together, we must ensure that the public receives the best possible care every time they come in contact with us – making them the real winners in this important effort!

A handwritten signature in black ink that reads "Doris Grinspun". The signature is stylized and includes a long horizontal flourish underneath the name.

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# How to Use This Document

This nursing Best Practice Guideline (BPG)<sup>G\*</sup> is a comprehensive document that provides resources for evidence<sup>G</sup>-based nursing practice. It is not intended to be a manual or “how to” guide, but rather a template to guide best practices associated with enhancing person- and family-centred care<sup>G</sup> and the partnerships between health-care providers<sup>G</sup>, the person<sup>G</sup>, and their family<sup>G</sup> within the context of the therapeutic relationship<sup>G</sup> to manage health<sup>G</sup>. The Guideline should be reviewed and applied in accordance with both the needs of individual organizations or practice settings and the needs and preferences of persons and their families accessing the health system for care and services. In addition, the Guideline offers an overview of appropriate structures and supports for providing the best possible evidence-based care.

Nurses<sup>G</sup>, other health-care providers, and administrators who lead and facilitate practice changes will find this document invaluable for developing policies, procedures, protocols, educational programs and assessment, interventions, and documentation tools. Nurses and other health-care providers in direct care will benefit from reviewing the recommendations and the evidence that supports them. We particularly recommend that practice settings adapt these guidelines in formats that are user-friendly for daily use.

If your organization is adopting this Guideline, we recommend you follow these steps:

1. Assess your nursing and health-care practices using the recommendations in this Guideline,
2. Identify which recommendations will address needs or gaps in services, and
3. Develop a plan for implementing the recommendations.

Implementation resources, including the RNAO *Toolkit: Implementation of Best Practice Guidelines* (2012d) are available at [www.RNAO.ca](http://www.RNAO.ca). We are interested in hearing how you have implemented this Guideline. Please contact us to share your story.

\* Throughout this document, terms marked with a superscript G (<sup>G</sup>) can be found in the Glossary of Terms ([Appendix A](#)).

## Purpose and Scope

**Best practice guidelines** are systematically developed statements designed to assist nurses working in partnership with persons and their families to make decisions about health care and services (Field & Lohr, 1990). This nursing Best Practice Guideline (BPG) is intended to replace the RNAO BPG *Client Centred Care* (2002) and its supplement (2006a). It is to be used by nurses and other members of the interprofessional health-care team<sup>G</sup> to enhance the quality of their partnerships with individuals accessing care, ultimately improving clinical outcomes and the person and family's experience<sup>G</sup> of health care through the use of evidence-based person- and family-centred-care practices.

In June 2014, RNAO convened an expert panel consisting of a group of individuals with expertise in establishing and using person- and family-centred-care practices in a variety of health-care settings. The RNAO expert panel was interprofessional in composition, comprising individuals holding clinical, administrative, and academic positions in a range of health-care organizations, practice areas, and sectors. These experts work with persons of all ages receiving care and services in different types of health-care settings (acute, long-term, and home health care, and in the community in primary care, family health teams, and public health). Some work in organizations, such as Patients Canada (<http://www.patientscanada.ca/>), dedicated to partnering with patients and their families to bring their voices to health-care reform, and with community organizations dedicated to assisting persons living with mental health issues and targeting the social, economic, and environmental determinants of health<sup>G</sup>, such as Working for Change (<http://workingforchange.ca/>). The RNAO expert panel also included patients.

The expert panel established the purpose and scope of this Guideline. The purpose of this Guideline is to promote the evidence-based practices associated with person- and family-centred care, and to help nurses and other health-care providers acquire the knowledge and skills necessary to become more adept at practising person- and family-centred care. The recommendations will help nurses and other health-care providers gain the knowledge required to partner and develop empowering relationships with persons accessing care and their families, in order to optimize health and wellness over their life continuum. This evidence-based approach, combined with a perspective that recognizes the place of the person at the centre of health care, will improve individuals' experience of and satisfaction with the care and services provided within the health system. It applies to all domains of nursing practice, including clinical, administration, and education.

This Guideline provides best practice recommendations in three main areas:

- Practice recommendations<sup>G</sup> are directed primarily to nurses and other health-care providers on the interprofessional team who provide direct care to persons in health-system settings (e.g., acute, long-term care, and home health care) and in the community (e.g., primary care, family health teams, and public health).
- Education recommendations<sup>G</sup> are directed to those responsible for staff and student education, such as educators, quality improvement teams, managers, administrators, and academic and professional institutions.
- System, organization, and policy recommendations<sup>G</sup> apply to a variety of audiences, depending on the recommendation. Audiences include managers, administrators, policy-makers, nursing regulatory bodies, academic institutions, and government bodies.

For optimal effectiveness, recommendations in these three areas should be implemented together to improve the person's experience of and satisfaction with the quality<sup>G</sup> of care, and to promote the use of person- and family-centred-care practices to enhance the interprofessional team's ability to partner within the context of the therapeutic relationship with persons and their families for the purpose of improving health. It is acknowledged that competencies associated with person- and family-centred care may vary among nurses and other health-care providers within interprofessional teams.



The application of person- and family-centred-care practices as outlined in this Guideline will be affected by various factors, including: individual organizations' policies and procedures; the organization's preferred terminology for the concept and associated components; government legislation (health and non-health – e.g., Ontario Ministry of Health and Long-Term Care, Ontario Ministry of Education, Ontario Ministry of Finance, etc.); and the demographic and socioeconomic characteristics of the person accessing care and services (e.g., infant, adolescent, adult, older person, person living with a disability, etc.).

## Person- and Family-Centred Care and Its Components

For application and consistency in practice, concepts and their respective components require clear, scientific, and well-developed definitions that are agreed upon by theorists, researchers, and practitioners (Mikkelsen & Frederiksen, 2011; Morse, Hupcey, Penrod, & Mitcham, 2002). A mature concept forms the links between theory, practice, and research. For the purpose of this Guideline, the expert panel supported the use of the term *person- and family-centred care*. The concept of person- and family-centred care is an example of a concept for which multiple terms, components, and definitions exist. The literature has described this practice as a practice–theory; a paradigm; a philosophy; and an approach to, or model of, care. The lack of uniformity in defining and describing the concept of person- and family-centred care and its associated dimensions has created an ongoing theory–practice gap that presents challenges related to implementation in practice at all levels of the health system (micro level<sup>G</sup>, meso level<sup>G</sup>, and macro level<sup>G</sup>).

Various terms have been used interchangeably across health-care organizations, settings, and in the literature to refer to the individual with whom health-care providers establish a therapeutic relationship for the purposes of partnering for health (e.g., person, client, patient, consumer, user, individual, family, etc.) and to describe the attributes of care delivery (e.g., -centred care, -focused care, -oriented care, -directed care, -driven care, etc.). While there are similarities among these terms and attributes, there are also distinguishing characteristics (de Silva, 2014; Greene, Tuzzio, & Cherkin, 2012; Guion, Mishoe, Passmore, & Witter, 2010; McMillan et al., 2013; Morgan & Yoder, 2012; National Ageing Research Institute, 2006).

For example, in the literature, person-centred care has been described as a move away from the biomedical model (i.e., the person as a disease requiring diagnosis and treatment) and toward coming to know the whole person and their experience of health over time (Olsson, Jakobsson Ung, Swedberg, & Ekman, 2013; Starfield, 2011). Other descriptions have viewed patient-centred care as a moral concept and philosophy, considering it to be the right thing to do when designing and delivering respectful, humane, and ethical care (Duggan, Geller, Cooper, & Beach, 2006; Edvardson & Innes, 2010). This ethical perspective envisions health-care providers as demonstrating person-centred-care attitudes and behaviours<sup>G</sup> that are respectful of the whole person and their preferences, are culturally sensitive, and involve the sharing of power within a therapeutic alliance to improve clinical outcomes and satisfaction with care (Duggan et al., 2006; Edvardsson, Winblad, & Sandman, 2008; State of Victoria Department of Health, 2012).

To add to the term's complexity, the Institute of Medicine Committee defines patient-centered care as care that is based on healing relationships (which include both emotional and physical components) and which includes the involvement of family and friends. In this perspective, the person is in control of their care because information and education is provided to assist them with making decisions about their health over their lifespan (Greene et al., 2012). The World Health Organization sees person-centred care as a broad concept in which the provision of care and services encompasses not only the health of the individual but also their family, culture<sup>G</sup>, and community. This view has a wider focus on global strategies designed to improve factors related to the social, economic, and environmental determinants of health, and targets disease prevention and public health of populations (Stein, Stukator Barbazza, Tello, & Kluge, 2013; World Health Organization [WHO], 2007b, 2010).

It is important to acknowledge that person- and family-centred care focuses on the *whole person* as a unique individual and not just on their illness or disease. In viewing the individual through this lens, health-care providers come to know and understand the person’s life story, experience of health, the role of family in the person’s life, and the role they may play in supporting the person to achieve health.

## Use of the Term “Person” in This Guideline

We have noted the various terms applied to the individual with whom health-care providers establish a therapeutic relationship for the purposes of partnering for health. In this Guideline, the only term that will be used is “person.” As used in this Guideline, the term is inclusive of the individual *and their family*. A person’s “family” includes all those whom the person identifies as significant in his or her life (e.g., parents, caregivers, friends, substitute decision-makers<sup>G</sup>, groups, communities, and populations). Exceptions to the use of this terminology occur in discussions of literature (e.g., studies, reports, etc.) that use alternative terms.

For more information about this Guideline, including the Guideline development process and the systematic review<sup>G</sup> and search strategy, refer to [Appendices B and C](#).



# Summary of Recommendations

This Guideline replaces the RNAO BPG *Client Centred Care* (2002) and its supplement (2006a).

We have used these symbols for the recommendations:

- ✓ No change was made to the recommendation as a result of the systematic review evidence.
- ✚ The recommendation and supporting evidence were updated with systematic review evidence.

**NEW** A new recommendation was developed based on evidence from the systematic review.

PRACTICE RECOMMENDATIONS		LEVEL OF EVIDENCE	STATUS
1.0 Assessment	<p><b>Recommendation 1.1:</b></p> <p>Establish a therapeutic relationship with the person using verbal and non-verbal communication strategies to build a genuine, trusting, and respectful partnership.</p>	III	✚
	<p><b>Recommendation 1.2:</b></p> <p>Build empowering relationships with the person to promote the person’s proactive and meaningful engagement as an active partner in their health care.</p>	Ia	<b>NEW</b>
	<p><b>Recommendation 1.3:</b></p> <p>Listen and seek insight into the whole person to gain an understanding of the meaning of health to the person and to learn their preferences for care.</p>	Ia	<b>NEW</b>
	<p><b>Recommendation 1.4:</b></p> <p>Document information obtained on the meaning and experience of health to the person using the person’s own words.</p>	V	<b>NEW</b>

PRACTICE RECOMMENDATIONS		LEVEL OF EVIDENCE	STATUS
2.0 Planning	<p><b>Recommendation 2.1:</b></p> <p>Develop a plan of care in partnership with the person that is meaningful to the person within the context of their life.</p>	la	<b>NEW</b>
	<p><b>Recommendation 2.2:</b></p> <p>Engage with the person in a participatory model of decision making, respecting the person’s right to choose the preferred interventions for their health, by:</p> <ol style="list-style-type: none"> <li>1) Collaborating with the person to identify their priorities and goals for health care;</li> <li>2) Sharing information to promote an understanding of available options for health care so the person can make an informed decision; and</li> <li>3) Respecting the person as an expert on themselves and their life.</li> </ol>	la	<b>NEW</b>
3.0 Implementation	<p><b>Recommendation 3.1:</b></p> <p>Personalize the delivery of care and services to ensure care is not driven from the perspective of the health-care provider and organization, by collaborating with the person on:</p> <ol style="list-style-type: none"> <li>1) Elements of care;</li> <li>2) Roles and responsibilities in the delivery of care; and</li> <li>3) Communication strategies.</li> </ol>	la	<b>NEW</b>
	<p><b>Recommendation 3.2:</b></p> <p>Partner with the person to tailor strategies for self-management of care that are based on the person’s characteristics and preferences for learning.</p>	V	<b>NEW</b>
4.0 Evaluation	<p><b>Recommendation 4.1:</b></p> <p>Obtain feedback from the person to determine the person’s satisfaction with care and whether the care delivered was person- and family-centred.</p>	la	<b>NEW</b>

EDUCATION RECOMMENDATIONS		LEVEL OF EVIDENCE	STATUS
5.0 Education	<p><b>Recommendation 5.1:</b></p> <p>Educate health-care providers at a minimum on the following attributes of person- and family-centred care to improve the person’s clinical outcomes and satisfaction with care:</p> <ol style="list-style-type: none"> <li>1) Empowerment;</li> <li>2) Communication; and</li> <li>3) Shared decision making.</li> </ol>	la	<b>NEW</b>
	<p><b>Recommendation 5.2:</b></p> <p>Educational institutions incorporate this Guideline into the curricula for nurses and, as appropriate, for other health-care providers.</p>	V	<b>+</b>

SYSTEM, ORGANIZATION AND POLICY RECOMMENDATIONS		LEVEL OF EVIDENCE	STATUS
6.0 System, Organization and Policy	<p><b>Recommendation 6.1:</b></p> <p>Create an organizational culture that exemplifies its commitment to person- and family-centred care by:</p> <ol style="list-style-type: none"> <li>1) Demonstrating leadership and commitment to this approach to care;</li> <li>2) Involving the person in co-designing health programs and services; and</li> <li>3) Building healthy work environments for all health-care providers.</li> </ol>	V	<b>NEW</b>
	<p><b>Recommendation 6.2:</b></p> <p>Design an environment that demonstrably improves the person’s experience of health care by:</p> <ol style="list-style-type: none"> <li>1) Creating healing environments;</li> <li>2) Being flexible and partnering to personalize care routines;</li> <li>3) Improving access to care and services;</li> <li>4) Enhancing the continuity and coordination of care and services during transitions; and</li> <li>5) Providing continuity of caregivers.</li> </ol>	V	<b>NEW</b>

SYSTEM, ORGANIZATION AND POLICY RECOMMENDATIONS		LEVEL OF EVIDENCE	STATUS
6.0 System, Organization and Policy	<p><b>Recommendation 6.3:</b></p> <p>Collect continuous feedback from the person to determine whether their experience with health care and services was person- and family-centred, and utilize this feedback to make improvements at all levels of the health system.</p>	III	<b>NEW</b>
	<p><b>Recommendation 6.4:</b></p> <p>Government agencies and regulatory bodies must monitor, measure, and utilize information from organizations regarding the person’s experience of health care to improve health-system performance.</p>	Ia	<b>NEW</b>



# Interpretation of Evidence

*Levels of evidence* are assigned to study designs to rank how well that design is able to eliminate alternate explanations of the phenomena under study. The higher the level of evidence, the greater the likelihood that the relationships presented between the variables are true. Levels of evidence do not reflect the merit or quality of individual studies.

## Levels of Evidence

Ia	Evidence obtained from meta-analysis <sup>6</sup> or systematic reviews <sup>6</sup> of randomized controlled trials <sup>6</sup> , and/or synthesis of multiple studies primarily of <i>quantitative</i> research.
Ib	Evidence obtained from at least one randomized controlled trial.
IIa	Evidence obtained from at least one well-designed controlled study <sup>6</sup> without randomization.
IIb	Evidence obtained from at least one other type of well-designed quasi-experimental study <sup>6</sup> , without randomization.
III	Synthesis of multiple studies primarily of <i>qualitative</i> research <sup>6</sup> .
IV	Evidence obtained from well-designed non-experimental observational studies, such as analytical studies <sup>6</sup> or descriptive studies <sup>6</sup> , and/or qualitative studies.
V	Evidence obtained from expert opinion or committee reports, and/or clinical experiences of respected authorities.

Adapted from the Scottish Intercollegiate Guidelines Network (Scottish Intercollegiate Guidelines Network [SIGN], 2011) and Pati (2011).

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Declarations of interest that might be construed as constituting an actual, potential or apparent conflict were made by all members of the Registered Nurses' Association of Ontario expert panel, and members were asked to update their disclosures regularly throughout the guideline development process. Information was requested about financial, intellectual, personal and other interests and documented for future reference. No limiting conflicts were identified.

Further details are available from the Registered Nurses' Association of Ontario.



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# Stakeholder Acknowledgement

As a component of the guideline development process, the Registered Nurses' Association of Ontario is committed to obtaining feedback from nurses from a wide range of practice settings and roles, knowledgeable administrators and funders of health-care services, and stakeholder<sup>G</sup> associations. Stakeholders representing diverse perspectives were solicited\* for their feedback, and the Registered Nurses' Association of Ontario wishes to acknowledge the following individuals for their contribution in reviewing this Nursing Best Practice Guideline.

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\*Stakeholder reviewers are individuals who have expertise in the subject matter of the guideline or are representatives of organizations involved in implementing the guideline or are affected by its implementation. Reviewers may be nurses and other point-of-care health-care providers, nurse executives, administrators, research experts, members of the interdisciplinary team, educators, nursing students, or patients. RNAO aims to solicit stakeholder expertise and perspectives representing a diversity of health-care sectors, roles within nursing and other professions (e.g., clinical practice, research, education, and policy) and geographic locations.

Stakeholder reviewers for RNAO guidelines are identified in two ways. First, stakeholders are recruited through a public call issued on the RNAO website (<http://rnao.ca/bpg/get-involved/stakeholder>). Second, key individuals and organizations with expertise in the guideline topic area are identified by the RNAO guideline development team and expert panel and are directly invited to participate in the review.

Reviewers are asked to read a full draft of the guideline and participate in the review prior to its publication.

Stakeholder feedback is submitted on-line by completing a survey questionnaire. The stakeholders are asked the following questions about each recommendation:

- Is this recommendation clear?
- Do you agree with this recommendation?
- Does the evidence support this recommendation?
- Does this recommendation apply to all roles, regions and practice settings?

The survey also includes opportunity to include comments and feedback for each section of the guideline.

Survey submissions received are compiled and feedback is summarized by the RNAO guideline development team. The RNAO expert panel reviews and considers all feedback and, if necessary, modifies the guideline content and recommendations prior to publication to address the feedback received.

Stakeholder reviewers have given consent to the publication of their names and contact details in this guideline.

## Background

In Canada and other countries such as Australia, England, and the United States, initiatives to improve the experience and delivery of care to the person and their family by health-care providers and organizations are underway (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2011; Baker, 2014; Lewis, 2009; National Voices, 2014a). Many of these initiatives are partnering with individual users (the person and their family) to assist with the development of strategies to improve the quality, effectiveness, and efficiency of care and service delivery at all levels of the health system (micro, meso, and macro). Partnering with individual users ensures the person is central to and the focus of system reform (Conway et al., 2006; Johnson et al., 2008; WHO, 2007a).

Achieving quality outcomes and satisfaction with health and system performance requires a person- and family-centred approach to care that builds true partnerships between the person and health-care providers (Baker, 2014; Harvey Picker Centre of Innovation and Applied Research in Long-Term Care, 2013). In its document *People-Centered Health Care: A Policy Framework* (2007a), WHO provides guidance to governments to help them bring about health reform and re-establish the focus on the health and well-being of people and their communities. It is anticipated that governments and organizations that use this framework will be able to engage people and their communities to participate in health-system reform in order to improve health and clinical outcomes, continuity of care, safety, and individuals' access to and satisfaction with services (WHO, 2014). Some organizations are also working to identify best practices associated with person- and family-centred care in order to increase individual users' engagement as real partners, improve the quality of care, and increase users' satisfaction and experience with services (Accreditation Canada, Canadian Foundation for Healthcare Improvement, Institute for Patient and Family-Centered Care, Picker Institute and Institute for Healthcare Improvement, and The Change Foundation).

Countries such as Canada, the United States, Australia, and England are also reforming their primary-care services to ensure that health care and services are focused on and organized around *the person* rather than the health-care providers and the system. Through these reforms, the focus of primary care shifts from the person's disease to encompass the whole person; care becomes accessible, comprehensive, integrated, coordinated, and recognized as a continuous partnership between the provider and the person to manage fluctuating states of health over time (RNAO, 2014c; Starfield, 2011). Furthermore, the Agency for Healthcare Research and Quality (2014b) characterizes patient-centred care as primary care that focuses on and respects the whole person *as a partner*, and that meets individual needs, preferences, and priorities for care and services. The primary care medical home model<sup>G</sup> developed in the United States is an example of an approach that seeks to improve patient-centred primary care and reorganize the delivery of services provided to people living with chronic disease.

## Movement Toward Person- and Family-Centred Care in Canada

In Canada within the last decade, a number of provincial initiatives have focused on putting the person at the centre of health-system reform in order to improve the quality of care and service delivery (Saint Elizabeth, 2011). The following are examples of initiatives, government legislation, and organizations that illustrate the movement toward person- and family-centred care at all levels of the health system:

- *Local Health System Integration Act, 2006* (2006): Passed by the Ontario government, this legislation established 14 Local Health Integration Networks (LHIN) responsible for improving local community engagement throughout the province in planning, coordinating, and funding each region's health services. The Act transferred significant power for making decisions to the community level, enabling local health systems to focus on the needs of individual communities.

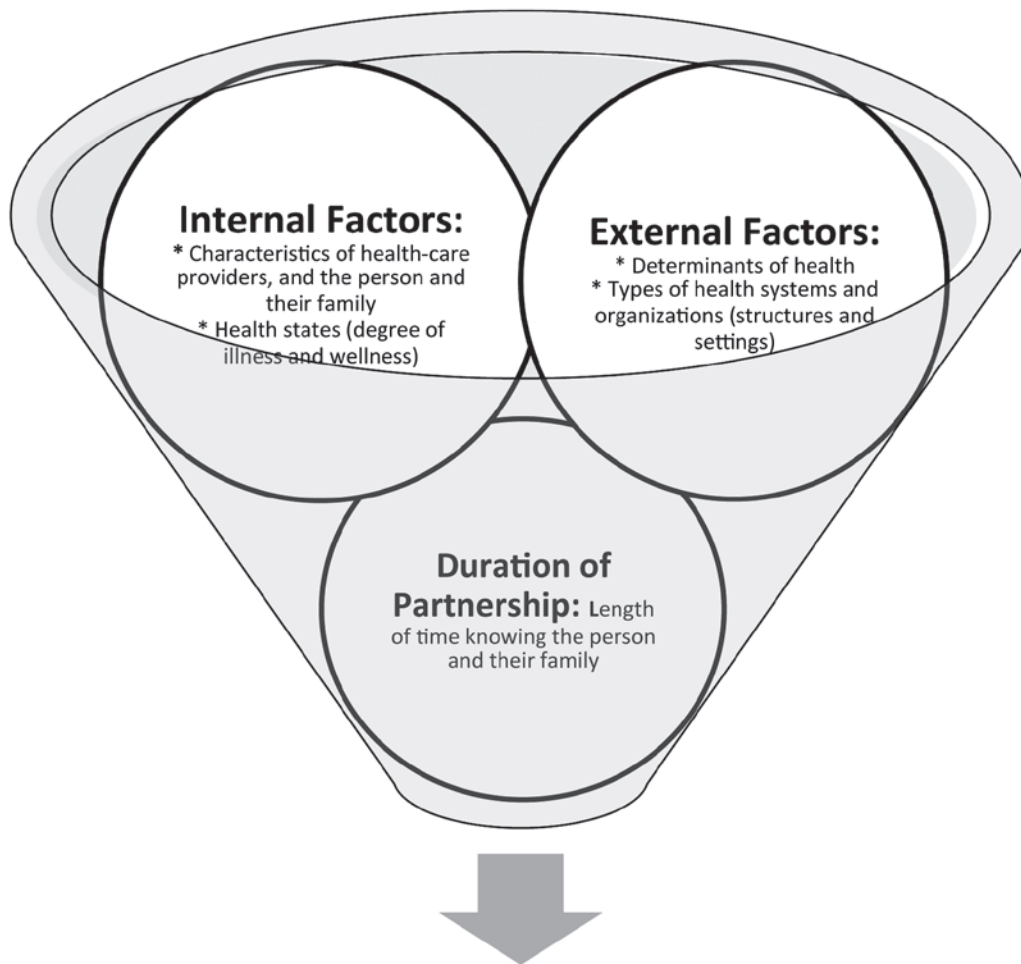
- *Primary Health Care Charter—A Collaborative Approach* (British Columbia Ministry of Health, 2007): This initiative commits to making primary health care in the province more client-centred by promoting patients and families as partners in care, focusing on the alignment and integration of services, and communicating key information regarding decisions on health care and service reforms.
- *For Patients' Sake—Patient First Review Commissioner's Report to the Saskatchewan Minister of Health* (Dagnone, 2009): This extensive review focused on the patient's experience of care, as well as on management of the health system. Research conducted with patients, families, and communities made it clear that a renewed commitment to putting patients first was required, both in the delivery of services and program and policy design and implementation. The report concluded that the health-care system must become more patient and family centred.
- *Alberta Health Act Consultation Report—Putting People First* (Horne, 2010a, 2010b): This report, created following a province-wide consultation process, sets out recommendations for the development of new health legislation that puts people first and for improvements to the existing health system. Recommendations include the implementation of a mandated Health Charter acknowledging the partnership for health that must exist between individuals, communities, health-care providers, and their government, as well a framework for public engagement.
- *Excellent Care for All Act, 2010* (2010): This Ontario legislation was created to improve the experience of individuals accessing the health-care system through quality improvement initiatives aimed at putting the person at the centre of system reform and optimizing service delivery for health and wellness.
- *Health Care Transformation in Canada* (Canadian Medical Association [CMA], 2010): This document outlines the CMA's support for a patient-centred system and culture through the development of a foundational Charter for Patient-Centred Care.
- *Patients for Patient Safety Canada* (Canadian Patient Safety Institute, 2010): This is a patient-led program of the Canadian Patient Safety Institute that champions the patient's voice, experience and perspective to ensure initiatives that advance safe healthcare are patient-centred.
- *Principles to Guide Health Care Transformation in Canada* (CMA & Canadian Nurses Association [CNA], 2011): This document outlines guiding principles for the transformation of Canada's health-care system, including: (a) enhancing the health-care experience (putting the patient at the centre of health-care service delivery and improving the quality of care); (b) improving population health (through health promotion<sup>G</sup> and disease/injury prevention<sup>G</sup>, ensuring equitable access, and addressing the social, economic, and environmental determinants of health); and (c) improving value for money (ensuring timely and cost-effective care to sustain the system, adequate resourcing, and accountability).
- *The Change Foundation's Journey Into the World of Patient Experience* (The Change Foundation, 2013): The Change Foundation is focused on improving the patient's experience of care through system change projects such as Partners Advancing Transitions in Healthcare (PATH) and PANORAMA. These projects promote patient and caregiver involvement in terms of sharing their experiences and views on health care and services and providing advice regarding the work required for system reform.

- *Rebuilding Healthcare Together: The Provincial Health Plan 2013–2018* (Province of New Brunswick, 2013): This provincial plan was developed with extensive community engagement and supports the move toward a client-centred health-care system. It recommends the establishment of partnerships between the government, health settings and health-care providers, and the people of New Brunswick to strengthen and ensure the integration of services close to home so that people can continue to live in their communities.
- *The Canadian Hospital Experiences Survey* (Canadian Institute for Health Information, 2014): The Canadian Institute for Health Information created this survey (based on the Hospital Consumer Assessment of Healthcare Providers and Systems) to gather information on patients' experiences in in-patient settings. The survey data obtained from organizations across Canada will be used for health-system benchmarking and will inform quality improvement initiatives aimed at enhancing the delivery of care and services.
- *National Research Corporation Canada*: This corporation is committed to measuring and improving patients' and families' experiences of care and their satisfaction with the health system by encouraging organizations to address the eight dimensions of care that matter most to patients (see [Appendix D](#)).
- *The Registered Nurses' Association of Ontario (RNAO)*: Among the publications of this professional nursing organization is *Enhancing Community Care for Ontarians* (RNAO, 2012a; 2014b), a report that provides a model, known as the ECCO model, that focuses on primary- and community-care transformation with the intent to: (1) create an integrated health system responsive to the complex needs of people (client-centred) and their communities; and (2) enable whole-system regional planning (coordination of care and services) to avoid duplication and inefficiencies, thereby facilitating sustainability of the system for Ontarians. More information on ECCO can be accessed at: [www.RNAO.ca/ecco](http://www.RNAO.ca/ecco).

## Health-Care Partnerships

In 1998, the authors of *Partnerships in Healthcare: Transforming Relational Process* suggested that the ability to form and sustain true partnerships was the most important competency<sup>G</sup> for health-care providers to acquire. To this day, creating partnerships remains the focus of health-system reform (Suchman, Botelho, & Hinton-Walker, 1998). Health-care providers who truly partner and attend to the relational processes of care (i.e., information sharing and assisting the person with the decision-making process based on the person's capacity<sup>G</sup>) rather than focusing only on treating the person's disease help the person achieve goals for their health that they cannot achieve alone (Suchman, 2006). Person- and family-centred care must be based on the development of a true partnership within the therapeutic relationship that recognizes, supports, and values the diversity, distinguishing features, and contributions of all participants (the person, the person's family, and health-care providers) and encourages genuine responsive actions and behaviours. Health-care partnerships are not linear or static. Rather, they are evolving and dynamic, and affected by many internal and external factors as well as by the duration of the partnership (Suchman, 2006). Figure 1 illustrates the factors affecting these partnerships.

Figure 1. Factors Affecting Person- and Family-Centred-Care Partnerships



## Health-Care Partnerships: Evolving and Dynamic

Source: Developed by the RNAO expert panel.

### Common Themes in Person- and Family-Centred Care

When optimized, health-care partnerships can improve the autonomy<sup>G</sup> of individuals to make decisions related to their health care and can increase their satisfaction with care. Health-care providers must consider the factors that influence these partnerships and gain the knowledge and skills necessary to implement the principles, features, and dimensions of person- and family-centred care in practice. These include:

1. *Establishing a therapeutic relationship for true partnership, continuity of care, and shared decision making<sup>G</sup>*

The existence of a therapeutic relationship between the person and health-care providers is central to person- and family-centred care. Continuity in health-care providers (i.e., the person partnering with the same providers) and the establishment of a true collaborative partnership within the context of a therapeutic relationship over time can optimize the person's health and wellness (Duggan et al., 2006; McCance, McCormack, & Dewing, 2011; RNAO, 2002, 2006a, 2006b; Shaller, 2007; Starfield, 2011). A therapeutic relationship is required between health-care providers and the person seeking health services so they can establish trust, partner, and share decisions on appropriate health care and services.

2. *Care is organized around, and respectful of, the person*

For a person to be satisfied with health-care services, care must be organized with and around the person. It should be respectful and reflective of the person’s voice, needs, culture, values, beliefs, and changing health states and life circumstances (Frampton et al., 2008; RNAO, 2002, 2006a).

3. *Knowing the whole person (holistic care)*

A person is not defined by their disease or their illness. Therefore, person- and family-centred care includes the philosophy of holism. This philosophy acknowledges that a human being comprises many components (biological, psychological, emotional, physical, personal, social, environmental, cultural, and spiritual). Through a partnership established within the context of the therapeutic relationship, health-care providers come to know the whole person, their goals, beliefs and values, culture, experience of health and life circumstances, and care needs (Glass, Moss, & Ogle, 2012; Manley, Hills, & Marriot, 2011; National Ageing Research Institute, 2006; RNAO, 2014d; Shaller, 2007).

4. *Communication, collaboration, and engagement*

Moving toward person- and family-centred care requires a change in the health-care culture, as well as in the attitudes<sup>G</sup> and behaviours of health-care providers – specifically, their ability to develop relationships, communicate, collaborate, encourage partnerships, and share information related to decisions on health care and services (Cancer Journey Portfolio, 2012; Duggan et al., 2006; Harvey Picker Centre of Innovation and Applied Research in Long-Term Care, 2013; McMillan et al., 2013; Rathert, Wyrwich, & Boren, 2013; Shaller, 2007). To optimize health outcomes and improve the quality and safety of their services, organizations must support health-care providers to redesign their partnerships with persons receiving care. These partnerships must be supported by true collaborations. Therefore, health-care providers must use effective and therapeutic communication with the person, and promote their active engagement in decisions for their health (Frampton et al., 2008; Johnson et al., 2008; RNAO, 2002, 2006a).





# Practice Recommendations

## 1.0 ASSESSMENT

### RECOMMENDATION 1.1:

Establish a therapeutic relationship with the person using verbal and non-verbal communication strategies to build a genuine, trusting, and respectful partnership.

Level of Evidence = III

### Discussion of Evidence:

Within the therapeutic relationship, the ultimate goal of person- and family-centred care is building respectful partnerships based on the trust formed between health-care providers and the person (Alzheimer Society, 2011; College of Nurses of Ontario [CNO], 2013b; Foster, Whitehead, Maybee, & Cullens, 2013; Franzel, Schwiengershausen, Heusser, & Berger, 2013; Hobbs, 2009; Holmstrom & Roing, 2010; Kitson, Marshall, Bassett, & Zeitz, 2013; Morgan & Yoder, 2012; Pelzang, 2010; RNAO, 2002, 2006a, 2006b; Slater, 2006). The therapeutic relationship helps the nurse establish trust with the person and promote their autonomy to make decisions for their health (Alzheimer Society, 2011; Ciufu, Hader, & Holly, 2011; CNO, 2013b; Corlett & Twycross, 2006; Saint Elizabeth, 2011). A review aimed at improving the experience of care in the United Kingdom's National Health Service reports that people understand that there may be a lack of continuity in their health-care providers, but what they value most are good relationships with their health-care providers and working together in partnership to create and manage a plan for their health (National Institute for Health and Clinical Excellence [NICE], 2012, 2014).

The therapeutic relationship is seen as a partnership for the health of the person (National Ageing Research Institute, 2006; Pelzang, 2010; RNAO, 2002, 2006a, 2006b; Robinson, Callister, Berry, & Dearing, 2008). A nurse's ongoing therapeutic engagement with the person is essential to connecting with them in meaningful ways to alleviate both physiological and psychological vulnerabilities pertaining to their health (Alzheimer Society, 2011; Hobbs, 2009). This ongoing partnership helps create a non-judgmental environment in which: (a) the health-care provider comes to know the whole person, including their life history and goals for health; (b) the health-care provider respects that the person is an expert on themselves and their life situation; (c) the person comes to trust in the provider's knowledge and expertise on best practices for health; and (d) the health-care provider comes to know the extent to which the person wishes to be involved in decisions on care for their overall health and wellness (Arvidsson, Andre, Borgquist, & Carlsson, 2010; Glass et al., 2012; Greene et al., 2012; Kindig, 2006; National Ageing Research Institute, 2006; RNAO, 2002, 2006a, 2006b; Taylor, Sims, & Haines, 2013).

To come to know the whole person, health-care providers must possess effective communication skills so the person can feel safe discussing his or her health needs. Communication is a pre-requisite interpersonal skill<sup>G</sup> that is central to all interactions between health-care providers and the person (Alzheimer Society, 2011; CNO, 2013b; Foster et al., 2013; Foster, Whitehead, & Maybee, 2010; NICE, 2012, 2014; RNAO, 2002, 2006a, 2006b; Slater, 2006; Ward, 2005). A health-care provider's attitude within the therapeutic relationship is the most influential factor in determining a person's involvement in and their experience of care (Ambresin, Bennett, Patton, Sancu, & Sawyer, 2013; Duggan et al., 2006; Foster et al., 2010; Ward, 2005). Health-care providers communicate these attitudes to the person through verbal and non-verbal behaviours (communication) during the delivery of care, thereby influencing the person's experience of care in a positive or negative way (Ambresin

et al., 2013; Foster et al., 2010, 2013; Holmstrom & Roing, 2010; Pelzang, 2010). Literature on the experience of health services reports that nurses' professional warmth and listening are associated with increased satisfaction with care. In contrast, the more negative the attitude of the nurse, the more dissatisfied the person is with their care (NICE, 2012, 2014). To enhance the person's experience of care, health-care providers must have sympathetic presence<sup>G</sup> within the therapeutic relationship and demonstrate an understanding of the person's circumstances (knowledge of their emotional, physical, psychological, and spiritual states, and their hopes and fears) (ACSQHC, 2011; Aujoulat, d'Hoore, & Deccache, 2007; Hudon et al., 2012; McCormack & McCance, 2006).

Efforts to improve verbal and non-verbal communication within the therapeutic relationship will help build trust and enhance the partnership between health-care providers and the person (Grant, Adams, Bayliss, & Heisler, 2013). When communicating verbally, health-care providers should consider their timing, rate of speech, use of medical terminology, and vocal tone. In addition, health-care providers must be aware of their non-verbal communication and behaviours (e.g., listening, facial expressions, and body language), as these can validate what the person is saying and relay the importance of the person in the relationship as a partner in their health care (Alzheimer Society, 2011; Foster et al., 2013; NICE, 2012, 2014; RNAO, 2006b; Widger, Steele, Oberle, & Davies, 2009).

Table 1 presents some verbal and non-verbal communication strategies to assist nurses and members of the interprofessional team to set the stage for building genuine, trusting, and respectful person- and family-centred-care partnerships.



Table 1. Verbal and Non-Verbal Communication Strategies

<b>Verbal</b>	<ul style="list-style-type: none"> <li>■ Introduce yourself (name) and your professional status (e.g., registered nurse, registered practical nurse, occupational therapist, doctor).</li> <li>■ Explain your role, and the timeline of your involvement with the person’s care.</li> <li>■ Ask the person how they prefer to be addressed and always address the person by this name.</li> <li>■ Prior to initiating care, collaborate and seek the person’s agreement to proceed with care. This will ensure it is a good time for them and that you will have their attention.</li> <li>■ When proceeding with care, take the time to explain the care step by step and provide information using clear, simple, and straightforward language.</li> <li>■ Be aware of your body language, and be respectful when: (a) exploring the person’s story; (b) seeking answers related to their beliefs, values, culture, and what they know about their health and the impact of their health on their life; and (c) asking what they think they would like to have happen for their care.</li> <li>■ Be reassuring when they are expressing their fears.</li> <li>■ Do not rush the person. Provide them with time to process what is being said and to ask questions or provide feedback.</li> <li>■ Without rushing, encourage the person to tell their story and explore with them: (a) what they understand and are feeling about their experience of health, and (b) what is most important to them for their care.</li> <li>■ Use positive and non-judgmental responses when speaking. For example, use terms with positive associations, such as “health needs or diagnosis” instead of “problem.” When clarifying information provided by the person, re-state the information using the person’s words rather than applying your own language (e.g., “You said you eat chocolate every day” instead of “You don’t follow your diet”).</li> <li>■ Accept, repeat, and validate your understanding of any information (including thoughts and feelings) that the person provides about their experience of health and their care.</li> <li>■ Adjust your communication style (tone of voice, cadence, loudness of speech, pauses and silences) to accommodate the person’s needs (age and developmental stage, cognitive status, and language and literacy levels).</li> <li>■ Act as a resource. Give clear information in the person’s desired form of communication (written, verbal) that identifies all members of the interprofessional team within the person’s circle of care.</li> <li>■ Explore with the person how they want to raise concerns and ask questions, clarify information, and inquire who is responsible for their care.</li> <li>■ Provide clear and timely information in ways that are affirming (supportive and sincere) and useful to the person, and confirm with them that the communication met their needs.</li> <li>■ Reflect on – and ask the person, their family, and caregivers – whether your manner and style of communication is meeting their needs.</li> </ul>
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**Non-Verbal**

- Actively listen without interrupting; be open; accept and validate what the person is saying.
- Convey sympathetic presence and caring in order to deepen your understanding of the person’s needs (emotional intelligence).
- Give the person your full attention and use direct eye contact (if culturally appropriate) to observe the person while they are speaking.
- Display emotion that indicates warmth, kindness, friendliness, sadness, and compassion (as appropriate), demonstrating your sensitivity to the person’s verbalized thoughts, feelings, and situation.
- Demonstrate respect and courtesy through displays of non-verbal behaviour, such as shaking hands on initial contact with the person (if culturally appropriate), acknowledging you are listening by nodding your head, and remaining silent so the person can speak without being interrupted or rushed.
- Use touch if appropriate to offer reassurance to the person, keeping in mind some individuals are uncomfortable with touch (e.g., culture and past or present abuse).
- Use actions that display efficiency and competence in your delivery of care (e.g., showing efficiency, organization and skill when initiating an intravenous line).

*Sources:* Alzheimer Society, 2011; Ambresin et al., 2013; Aujoulat et al., 2007; CNO, 2013b; Foster et al., 2013; Frampton et al., 2008; NICE, 2012, 2014; RNAO, 2002, 2006a, 2006b; Robinson et al., 2008; Ward, 2005; Widger et al., 2009.

**RECOMMENDATION 1.2:**

Build empowering relationships with the person to promote the person’s proactive and meaningful engagement as an active partner in their health care.

**Level of Evidence = Ia**

**Discussion of Evidence:**

Empowerment<sup>G</sup> of all participants within the therapeutic relationship is one of the goals of person- and family-centred care (Aujoulat et al., 2007; Franzel et al., 2013; NICE, 2012, 2014; Slater, 2006). Empowering relationships enhance the partnership between the health-care provider and the person, and help promote the person’s proactive and preferred level of meaningful engagement in the management of their health (Clay et al., 2013; Corbett, Foster, & Ong, 2009; Corlett & Twycross, 2006; Laidsaar-Powell et al., 2013; Saint Elizabeth, 2011; Say, Murtagh, & Thomson, 2006). Promoting the person as an active partner means recognizing and valuing their potential and their strengths, sharing power with them, and working with them to create a plan for their health (Holmstrom & Roing, 2010; Mikkelsen & Frederiksen, 2011; Morgan & Yoder, 2012; Pelzang, 2010; RNAO, 2002, 2006a; Richmond PRA, 2013; Rodriguez-Osorio & Dominguez-Cherit, 2008; Simm, Hastie, & Weymouth, 2011). This, in turn, is empowering. A systematic review of randomized controlled trials found significantly improved results in health outcomes when persons were involved as partners in their care (Olsson et al., 2013).

In person- and family-centred care, all care is delivered within the context of a therapeutic relationship that promotes a respectful partnership where each participant understands and values what each individual brings to the relationship (Pelzang, 2010; RNAO, 2002, 2006a). This means that the person is recognized as the expert on themselves, their experience of health, and their life circumstances, and health-care providers are recognized as experts on evidence-based practices for care (Morgan & Yoder, 2012; National Ageing Research Institute, 2006; Pelzang, 2010; RNAO, 2002, 2006a). The active participation of the person in their care increases their empowerment and their ability to navigate the health system for care and services, and helps avoid potential adverse effects of treatment (McCance et al., 2011; McCormack & McCance, 2006; Starfield, 2011). Table 2 outlines health-care-provider behaviours that encourage empowerment.

**Table 2. Behaviours That Encourage Empowerment**

- Demonstrate an interest in the whole person as an individual.
- Intentionally start with what matters most to the person.
- Be respectful of each person’s diversity and their evolving capacity to manage their health.
- Take the time to be present, and actively listen (without judgment) to hear and learn about the person’s values, beliefs, culture, spirituality, wishes, interests, life circumstances, and experience of health (priorities, concerns, and preferences).
- Encourage the person to tell their story so that you can come to know and draw out information regarding what helps or hinders the person’s achievement of health.
- Facilitate choice and support the person’s autonomy, and demonstrate a belief in the person’s ability to make decisions for their health.
- Encourage the person to participate to their preferred level of involvement.
- Demonstrate sympathetic presence when the person expresses emotion.
- Encourage the person to voice any questions they may have about their health needs and care.
- Provide information and education to support the person in making decisions related to their health care.
- Do not rush interactions with the person. Provide the time necessary for the person to listen and absorb the information required to make a decision.

*Sources:* Aujoulat et al., 2007; Frampton et al., 2008; Hudon et al., 2012; National Research Corporation Canada, 2014; National Voices, 2014e; NICE, 2012, 2014; Olsson et al., 2013; Richmond PRA, 2013.

**RECOMMENDATION 1.3:**

Listen and seek insight into the whole person to gain an understanding of the meaning of health to the person and to learn their preferences for care.

Level of Evidence = Ia

## Discussion of Evidence:

Systematic reviews and meta-syntheses of the literature report that, early in the partnership for care, it is the responsibility of health-care providers to learn about the whole person to the extent possible in light of the degree to which the person is willing to engage in discussion. Learning about the whole person includes coming to know: (a) what makes the person a unique individual, (b) how the person perceives and experiences health (the personal meaning), and (c) how the person's health affects their life priorities (Ambresin et al., 2013; Foster et al., 2013; Franzel et al., 2013; National Ageing Research Institute, 2006; Pelzang, 2010; Winsor et al., 2013). Nurses and other health-care providers should build such information-gathering into their assessment processes by listening, exploring, and seeking insight into the whole person to allow them to see beyond the person's disease or illness (Knops, Srinivasan, & Meyers, 2005; MacKean et al., 2012; NICE, 2012, 2014; Widger et al., 2009). Coming to know the whole person through ongoing assessments assists with creating and establishing a plan of care that has greater relevance to the person, based on their experience of health and their life circumstances (e.g., social, economic, and environmental determinants of health) (National Ageing Research Institute, 2006; Pelzang, 2010). The person's preferences for health care and services must be reassessed over time, as their needs may vary with changes in their health and life circumstances (Knops et al., 2005; Say et al., 2006; Widger et al., 2009).

The person's perspective informs the health-care provider of the context for the person's care needs. When interacting with health-care providers, people find it most meaningful when: (a) they are viewed from a holistic perspective (i.e., not seen just in the context of their disease or illness), (b) their experience of health is legitimized, (c) they are acknowledged as the expert on themselves and their life, and (d) they work in partnership with health-care providers to navigate the health system for care and services (Dancet et al., 2010; Holmstrom & Roing, 2010; Hudon et al., 2012; Morgan & Yoder, 2012; National Ageing Research Institute, 2006; NICE, 2012, 2014; Pelzang, 2010; Slater, 2006). The literature reports that knowing the whole person helps health-care providers keep the person's preferences central to planning and tailoring health services, which leads to improved health outcomes and satisfaction with care (Graffy, Eaton, Sturt, & Chadwick, 2009; Grant et al., 2013; MacKean et al., 2012; Renzaho, Romios, Crock, & Sonderlund, 2013; Richards et al., 2007; Winsor et al., 2013).

Health literacy<sup>6</sup> impacts overall health, so nurses must explore with the person their understanding of their health and their needs to self-manage care (National Voices, 2014b, 2014c, 2014d, 2014e; RNAO, 2012b). Table 3 indicates the types of questions that health-care providers should build into their assessment processes to respectfully explore and seek insight into the whole person, their experience of health, and their preferences and needs for planning their care.

**Table 3. Seeking Insight Into the Whole Person, Their Experience of Health, and Their Preferences and Needs**

Health-care providers should ask the person questions to determine the following:

- What they think their strengths and health needs are (perceptions, knowledge, and understanding of their health, to determine health literacy).
- What they are concerned about (fears, anxieties, and impacts [biopsychosocial] on them and their life).
- What they wish to happen for care (perceptions, desires, preferences, and expectations).
- What their priorities for care and services are (what is most important to them right now).
- What they think about their ability to manage their own health, and whether they feel they need assistance.
- What they feel must be taken into consideration when planning, coordinating, and delivering their care (beliefs, values, culture, religion, spiritual preferences, sexual orientation, etc.).
- Who they wish to involve in their care (circle of care) and the degree to which they wish them to be involved (roles and responsibilities for care).
- What information they think they require related to their health, the format in which they would like to receive the information (e.g., written, verbal, visual, electronic, language levels, and other preferences), and when would they like to receive the information (timing).

Sources: Foster et al., 2013; Franzel et al., 2013; Grant et al., 2013; Knops et al., 2005; Laidsaar-Powell et al., 2013; RNAO, 2002, 2006a; Say et al., 2006; Smith, Dwamena, Grover, Coffey, & Frankel, 2011; Ward, 2005; Widger et al., 2009; Winsor et al., 2013.

#### RECOMMENDATION 1.4:

Document information obtained on the meaning and experience of health to the person using the person's own words.

Level of Evidence = V

### Discussion of Evidence:

Nurses must document the information obtained on the meaning and experience of health to the person using the person's own words. This information will be used to diagnose, plan, coordinate, and implement health care and services (Salloum & Mezzich, 2011). Under Ontario's *Personal Health Information Protection Act, 2004* (2004), the person has a right to access their personal information in the health record. Health-care providers must inform the person of their right to review and contribute, in their own words, to the documentation of their care within the context of the organization's policy and procedure for individual access to health records (American Hospital Association & Institute for Patient- and Family-Centred Care, 2004; Frampton et al., 2008). Facilitating a person's wish to document in the health record supports the concept of ensuring documentation reflects their own words.

Documentation should include the person’s own words on the following aspects of health care and the delivery of services:

- The name they prefer to be addressed by;
- Their perceptions, knowledge, and understanding of their health history and current health and wellbeing (health literacy);
- Their strengths, concerns and fears, and how they feel their illness has affected them and their life;
- Their perceptions, desires, preferences, and expectations for their care;
- Their priorities for care and services (what is most important to them right now);
- Their thoughts and feelings about their ability to manage their own health, their self-identified strengths and whether they feel they need assistance;
- Considerations for planning, coordinating, and implementing care (e.g., beliefs, culture, sexual orientation, religion, spirituality, etc.);
- Who they wish to have involved in their health care (circle of care<sup>6</sup>) and the degree to which they wish them to be involved (roles and responsibilities for care); and
- What information they asked for related to their health, how they would like to receive this information (e.g., written, verbal, visual, electronic, language levels, and other preferences), and when would they like to receive the information (timing).

Effective documentation of this information will help inform other members of the health-care team about the meaning of health to the person and assist with continuity of care, quality, and safety when delivering health services to meet care needs (Conway et al., 2006; RNAO, 2002, 2006a).

## 2.0 PLANNING

### RECOMMENDATION 2.1:

Develop a plan of care in partnership with the person that is meaningful to the person within the context of their life.

Level of Evidence = Ia

### Discussion of Evidence:

To enhance the person’s experience of health care and services, the person must be invited to participate in all care conferences and planning meetings (Committee on Hospital Care & Institute for Patient- and Family-Centred Care, 2012; International Alliance of Patients’ Organizations, 2012; RNAO, 2002, 2006a; Saint Elizabeth, 2011). A person- and family-centred-care approach to planning enables the person to be an active partner with health-care providers in determining the goals and plans for care (National Voices, 2014a; RNAO, 2002, 2006a; Richmond PRA, 2013). A meta-synthesis of the literature and other reviews report that including the person in care planning personalizes care by acknowledging the person’s strengths, hopes, and preferences for care based on individual beliefs, values, culture, and life context (Dancet et al., 2010; Morgan & Yoder, 2012; Pelzang, 2010; Richards et al., 2007; Robinson et al., 2008; Thompson, 2009). The person’s perspective must be kept central during the planning process to ensure the plan of care is personalized, addresses the person’s unique needs and life circumstances, and consists of evidence-based strategies appropriate for the person’s health needs (Crandall, White, Schuldheis, & Talerico, 2007; National Ageing Research Institute, 2006; RNAO, 2002, 2006a; Taylor et al., 2013).



**RECOMMENDATION 2.2:**

Engage with the person in a participatory model of decision making, respecting the person's right to choose the preferred interventions for their health, by:

- 1) Collaborating with the person to identify their priorities and goals for health care;
- 2) Sharing information to promote an understanding of available options for health care so the person can make an informed decision; and
- 3) Respecting the person as an expert on themselves and their life.

**Level of Evidence = Ia**

## Discussion of Evidence:

When planning care and services, health-care providers should engage with the person in a participatory model of shared decision making, respecting their right to choose the preferred interventions for their health (Elwyn et al., 2012; Lewis, 2009; National Ageing Research Institute, 2006). A participatory model of decision making respects the person's right to choose the interventions for care that meet their health-care goals. A participatory model includes: (1) collaborating with the person to identify their priorities and goals for health care, (2) sharing information to promote an understanding of available options for health care so the person can make an informed decision, and (3) respecting the person as an expert on themselves and their life.

### Collaborating With the Person to Identify Priorities and Goals

During planning meetings, health-care providers must spend time with the person to come to know them and understand their life context from their perspective. This collaboration supports the identification of actual and potential health-care needs (CNO, 2014b; RNAO, 2002, 2006a). Health-care providers must partner with the person to identify their priorities and goals for care; be empowering; and act as a resource, providing information on the available evidence-based care options that are congruent with the person's strengths, life circumstances, beliefs, needs, values, and preferences (CNO, 2014b; Conway et al., 2006; Frampton et al., 2008; Grant et al., 2013; National Research Corporation Canada, 2014; NICE, 2012, 2014; RNAO, 2002, 2006a; Robinson et al., 2008). A narrative review of randomized controlled trials identified that using open-ended questions, providing information, and responding positively to the person is empowering and helps health-care providers assist the person to explore their experience, goals, and preferences for health care (Smith, Dwamena, Grover, Coffey, & Frankel, 2011). Table 4 contains sample questions that nurses and other members of the health-care team can ask to gain an understanding of the person's priorities and goals for care.

**Table 4. Seeking Priorities and Goals for Care**

Health-care providers should ask the following questions:

- What is this situation like for you?
- What are your questions?
- What is most important to you?
- What are your goals?
- What are your strengths?
- What do you hope happens?
- What do you see down the road?
- What are your concerns?
- How can we, your health team support you?

*Sources: RNAO, 2002, 2006a.*

With a mutual understanding of what matters the most to the person, the health-care provider and the person can discuss options, plan, and prioritize the care together that is meaningful to both the person and the health-care provider. The person's active involvement as a partner in care must be documented to show they were actively involved in the decision-making process and made informed choices with health-care providers for their plan of care.

### Sharing Information to Promote an Understanding of Options

It is important that the person understand the need to make a decision regarding care and that he or she receive adequate support from members of the health-care team during the decision-making process (Makoul & Clayman, 2006; NICE, 2012, 2014; RNAO, 2002, 2006a). The nurse and other members of the health-care team should be available to provide their clinical expertise and perspectives on evidence-based practices when deliberating and negotiating decisions regarding care (Ambresin et al., 2013; Foster et al., 2013; Makoul & Clayman, 2006; National Voices, 2014e). Health-care providers must support the person through a decision-making process<sup>G</sup> so they can choose their preferred option(s) for care (Frampton et al., 2008; National Research Corporation Canada, 2014; National Voices, 2014b; National Voices, 2014e).

When exploring options for care during planning meetings, nurses and other members of the health-care team should start the process by asking the person what they know about current and available options for their health care (knowledge) and explore what the person thinks he or she needs (information and teaching) based on their own experiences with their health and life circumstances (National Voices, 2014b; National Voices, 2014e; Ward, 2005). Table 5 contains sample questions that members of the health-care team can use to explore the person's knowledge about available options for care and identify care needs from the perspective of the person.

**Table 5. Exploring Knowledge About Options and Care Needs**

Health-care providers should ask the following questions:

- What do you understand your options to be?
- How do you see that happening?
- Can you picture that?
- What do you need in order to (...)?
- What information will you use?
- What would help you (...)?
- What do you see as your role in your care?
- What options are you willing and able to follow through on?
- What do you hope or believe this will achieve?

Sources: NICE, 2012, 2014; RNAO, 2002, 2006a.

The planning process for health services requires that, after considering the options available, the person, from their perspective, make a judgment and decide on the best option(s) for their care. Health-care providers should seek confirmation from the person that the choices being offered are consistent with what is important to the person and their life context, and confirm that the person feels they have received enough information to move forward with a decision on care (Foster et al., 2013; Makoul & Clayman, 2006; National Voices, 2014e; NICE, 2012, 2014; Ward, 2005). To enhance the judgment and decision-making process for the person on the available options, health-care providers must consider and address the following:

- The specialized knowledge required (e.g., information the person requires on the side effects and risks of different medications used to treat their illness);
- The person's values and goals;
- The benefits, harms (risks), and scientific uncertainties;
- Any viable alternative options;
- The time available to the person within which to make a decision; and
- The person's preferred degree of involvement in decisions about their care

(Leise, 2013; National Voices, 2014e; RNAO, 2002, 2006a).

The person must be given information on evidence-based treatment options in a way that enables them to make a decision (Elwyn et al., 2012; National Voices, 2014b, 2014e; NICE, 2012, 2014; RNAO, 2002, 2006a). The health-care provider must provide the information without bias or attempting to sway the person toward any one option (National Research Corporation Canada, 2014; National Voices, 2014b, 2014e; Stacey et al., 2014).

When planning care, decision aids<sup>G</sup> (e.g., pamphlets, videos, counseling, peer support, coaching, and tools) should be offered and used to supplement health-care providers' explanations of the available options for care (Légaré et al., 2010; National Voices, 2014e; NICE, 2012, 2014; Stacey et al., 2014). Decision aids provide structure to the decision-making process. They assist health-care providers in describing the potential benefits and harms (risks) to the person in a way that allows

the person to understand the implications of choosing one option of care over another. They also assist the person to come to a final decision on a preferred option for care based on what they value (cognitive, psychological, emotional, physical, social, cultural, and spiritual perspectives) and consider important for their health and life circumstances (Ambresin et al., 2013; Leise, 2013; Makoul & Clayman, 2006; NICE, 2012, 2014; RNAO, 2002, 2006a; Stacey et al., 2014; Winsor et al., 2013). For a list of organizations that offer decision aids for person- and family-centred care, refer to [Appendix E](#).

### Respecting the Person as an Expert on Themselves and Their Life

The person and their family (within the circle of care) must be the key decision-makers when planning health care and services (McCance et al., 2011; RNAO, 2002, 2006a; Saint Elizabeth, 2011). Sharing decisions on health care requires a mutual understanding that the person is the expert on themselves and their life situation, and that health-care providers are the experts on evidence-based practices and legislation in health care (Morgan & Yoder, 2012; National Ageing Research Institute, 2006; RNAO, 2002, 2006a; Robinson et al., 2008).

Often, a lack of communication or understanding of another's perspective gives rise to conflict (RNAO, 2012c). When planning care, it is the person's right to choose intervention strategies that meet their preferences and goals for care based on their beliefs, values, and life situation, even if others do not perceive the person's choice as the best one (Frampton et al., 2008; National Research Corporation Canada, 2014; NICE, 2012, 2014; RNAO, 2002, 2006a; Winsor et al., 2013). Health-care providers must be able to set aside their personal values and opinions, and respect that the person may have different priorities and may make a decision for their care that is different than the decision the health-care provider would make (NICE, 2012, 2014; RNAO, 2002, 2006a; Smith et al., 2011). During times of ethical conflict, health-care providers must not abandon the person but must continue to promote the person's health literacy in an empowering environment that is safe, free of shame and blame, and devoid of stigma (RNAO, 2012b). Health-care providers should listen, understand, and respond with information and resources (including legislation) to support informed decision making while honouring the person's choices for care and their health (CNO, 2013b; Frampton et al., 2008; National Research Corporation Canada, 2014; RNAO, 2002, 2006a; Smith et al., 2011).

## 3.0 IMPLEMENTATION

### RECOMMENDATION 3.1:

Personalize the delivery of care and services to ensure care is not driven from the perspective of the health-care provider and organization, by collaborating with the person on:

- 1) Elements of care;
- 2) Roles and responsibilities in the delivery of care; and
- 3) Communication strategies.

**Level of Evidence = Ia**

## Discussion of Evidence:

To enhance the person's experience of care, the delivery of health services should be flexible and planned around the needs of the whole person (Alzheimer Society, 2011; Ambresin et al., 2013; Frampton et al., 2008; McCance et al., 2011; Olsson et al., 2013; Saint Elizabeth, 2011). Encounters within the health system during fluctuating states of health causes physical and mental exhaustion, stress and suffering, and can impact a person's life (Foster et al., 2013). Systematic reviews of the literature report that health-care providers must anticipate the needs of the whole person in order to deliver services, understand the context of care (acute, long-term care, community, and primary care), and consider the uniqueness of each person and their ability to participate in their own care (Alzheimer Society, 2011; Ambresin et al., 2013; Brownie & Nancarrow, 2013; Conway et al., 2006; Dancet et al., 2010; Franzel et al., 2013; Thompson, 2009). Collaborating with the person on the following ensures that the delivery of care and services is personalized and not driven only from the perspective of the health-care provider and the organization: (1) the elements of care, (2) roles and responsibilities in the delivery of care, and (3) communication strategies (Alzheimer Society, 2011; Ciufu et al., 2011; Corlett & Twycross, 2006; Frampton et al., 2008; Mikkelsen & Frederiksen, 2011; Morgan & Yoder, 2012; National Voices, 2014a).

### Elements of Care

The way in which the delivery of care is personalized will depend on the wishes of the person (Morgan & Yoder, 2012; National Ageing Research Institute, 2006; Pelzang, 2010; Robinson et al., 2008; Thompson, 2009). Health-care providers can enhance the personalization of care delivery by seeking to understand the person's preferences and by collaborating with the person on elements of care such as the preferred time for personal care, meals, and meal scheduling; appointment times; priorities for setting an agenda when meeting with health-care providers; desired level of participation in change-of-shift reports; preferences for accessing the medical record; and family presence during resuscitation, rapid response, or responsive behaviours (e.g., wandering and aggression) (Ambresin et al., 2013; Dagnone, 2009; Frampton et al., 2008; Grant et al., 2013; McCormack & McCance, 2006; National Research Corporation Canada, 2014; National Voices, 2014e; Renzaho et al., 2013; Saint Elizabeth, 2011).

Nurses and other health-care providers should support family presence according to the wishes of the person (Ciufu et al., 2011; Frampton et al., 2008; RNAO, 2002, 2006a). Flexibility in visiting hours improves the person's experience of and satisfaction with health care and services. The literature reports no increase in health-care providers' workload or delay in the delivery of care with flexible visiting hours (Ciufu et al., 2011). Therefore, nurses should accommodate open visiting hours to meet the preferences of the person and their family. However, in situations when timing of care is critical and will have an impact on visiting hours, the nurse should explain the situation to the person in a manner that the person can understand, and come to a consensus on the timing of visits.

To improve the person's satisfaction and experience of health care, nurses must personalize the elements of care that support the person's physical comfort (Monsivais & Engebretson, 2011; National Research Corporation Canada, 2014; National Voices, 2014a; Tzelepis et al., 2014). This includes addressing the biomedical (biological and physiological) needs affecting the person's overall health. Two important dimensions that must be addressed are pain management and physical comfort (including help with activities of daily living) (ACSQHC, 2011; Conway et al., 2006; Frampton et al., 2008; National Research Corporation Canada, 2014; NICE, 2012, 2014; Saint Elizabeth, 2011). A recent review of the literature explored person- and family-centred approaches to care in long-term care facilities and identified that the basic physiological and safety needs of residents must be met prior to addressing higher-level functions (e.g., love, esteem, and self-actualization [see Maslow's hierarchy of needs which can be accessed at <http://psychclassics.yorku.ca/Maslow/motivation.htm>]) (Brownie & Nancarrow, 2013).

When there is a difference in the person's and the health-care provider's expectations for care, collaboration can assist in: (a) exploring the person's perspective; (b) exploring the health-care provider's and organization's perspective; (c) accepting there is a difference of opinion, without judgment; (d) creating a shared understanding of what everyone is willing to do; and (e) arriving at a mutually agreed-to solution and plan for the delivery of care and services (ACSQHC, 2011; Corlett & Twycross, 2006; Dagnone, 2009; Saint Elizabeth, 2011).

## Roles and Responsibilities in the Delivery of Care

To promote empowerment and management of care, all individuals within the circle of care must understand their roles and responsibilities in relation to the formal care team for each element of care (Corlett & Twycross, 2006; McBroom & Enriquez, 2009; Say et al., 2006). A qualitative meta-synthesis of the literature reported that persons living with chronic disease who played a role in managing their own care in a community program demonstrated a better understanding of their diagnosis, experienced fewer psychological and social barriers to care, and reported an increase in their socialization (Winzelberg, Williams, Preisser, Zimmerman, & Sloane, 2005).

Nurses must not assume they know what is best for the person who is receiving care and unilaterally decide the role and aspects of care that can be taken on by the person (Corlett & Twycross, 2006). Instead, they should collaborate with the person to determine what aspects of care delivery he or she feels are important to participate in, and discuss how this can be accomplished (e.g., parents bathing a premature infant in an intensive care setting so they can continue to bond during hospitalization) (Ciuffo et al., 2011; Corlett & Twycross, 2006; Franzel et al., 2013; Johnson et al., 2008; Mikkelsen & Frederiksen, 2011). Alternatively, if the person demonstrates an ambivalence or reluctance to participate in the delivery of aspects of care, health-care providers should support the person to participate to their desired level of engagement (Conway et al., 2006; Hudon et al., 2012; RNAO, 2002, 2006a).

## Communication Strategies

Effective two-way communication between health-care providers and the person is an important component in the delivery of health care and is essential to improving the person's experience of care (NICE, 2012, 2014). Often, the person lacks trust in their health-care providers and may believe that information on their condition is being withheld (National Research Corporation Canada, 2014). To reduce these fears and promote trust, safety, quality, and continuity of care, nurses and other health-care providers should establish effective communication processes to facilitate timely access to acceptable and accurate health information on the person's clinical status, progress and prognosis, and the processes of care (National Research Corporation Canada, 2014; RNAO, 2013a, 2014a).

The actions and behaviours of health-care providers are critical in the delivery of person- and family-centred care (Brownie & Nancarrow, 2013; Ciuffo et al., 2011; Corlett & Twycross, 2006). Therefore, communication strategies (direct eye contact, smiling, and displays of emotion) used by health-care providers should encourage the person to feel safe to express their feelings and ideas at every interaction, and help to further develop the therapeutic relationship with the person (MacKean et al., 2012; Widger et al., 2009). For example, parents of children in particular appreciate health-care providers who are able to display warmth, kindness, compassion, and sensitivity, especially when sharing bad news (Foster et al., 2013; Widger et al., 2009). Table 6 sets out some features of health-care-provider behaviour and communication that are known to improve the effectiveness of care if used when interacting with the person. For a list of organizations that offer tools or programs that support improvements in health-care provider communication for person- and family-centred care, refer to [Appendix E](#).

**Table 6. Behaviours That Improve Effectiveness of Care**

- Using open-ended communication skills (where appropriate) when exploring the person’s experience of health care.
- Listening without interrupting.
- Eliciting and responding to emotion with the use of empathy, understanding, and caring.
- Being sensitive to non-medical dimensions of care (culture beliefs, values, and spirituality).
- Attending to physical comforts.
- Providing hope, expressing support, and being willing to help.
- Providing time for care (not rushing).
- Using a positive approach by motivating, encouraging, and legitimizing the person’s experiences of health.
- Giving specific evidence-based information and recommendations for behavioural change.
- Explaining care and treatment by linking it to the person’s health-care needs.
- Tailoring communication strategies based on the health literacy, culture, and language needs of the person and their family.
- Advising, acknowledging, and accepting the person’s choices for care and services.

Sources: ACSQHC, 2011; Aujoulat et al., 2007; Duggan et al., 2006; Hudon et al., 2012; Makoul & Clayman, 2006; Olsson et al., 2013; RNAO, 2002, 2006a; Smith et al., 2011.

**RECOMMENDATION 3.2:**

Partner with the person to tailor strategies for self-management of care that are based on the person’s characteristics and preferences for learning.

**Level of Evidence = V**

**Discussion of Evidence:**

All people can struggle with the challenges of managing their health, so nurses have a role to play in ensuring the person gains the knowledge, skills, and behaviours (health literacy) necessary for self-management<sup>G</sup> – the ability to promote, maintain, and improve their health (RNAO, 2012b). Health literacy, which is directly related to a person’s ability to self-manage their care, means that the person can access, understand, appraise, and apply health information when making decisions, and has the ability or supports required to overcome any relational, cognitive, affective, physical, psychological, and social barriers (language, cultural, spiritual, symbolic, and life experiences) that interfere with their ability to self-manage their care (Foster et al., 2013; National Voices, 2014b, 2014c, 2014d, 2014e; RNAO, 2002, 2006a, 2012b; Widger et al., 2009; Winsor et al., 2013).

To promote the person’s ability to self-manage care (to the extent that the person is able), nurses must partner with the person to tailor strategies (information and education) that are based on the person’s individual characteristics and preferences for learning (National Voices, 2014b, 2014d; RNAO, 2002, 2006a, 2012b; Saint Elizabeth, 2011). Health-care providers can support the development of the person’s health literacy and build the person’s confidence to carry out actions and activities needed for their health and wellbeing by using a partnership model for learning that is holistic and which includes the following:

- Empowering the person within the context of the therapeutic relationship to acquire the knowledge and skills necessary for self-management of care;
- Acknowledging the person’s strengths, expertise, and contributions to self-management of care;
- Determining the person’s existing knowledge, in order to begin the process of creating links between old and new knowledge;
- Sharing knowledge and information freely, so the person begins to comprehend and gain insight into what is needed to promote, maintain, and improve their health. This involves:
  - tailoring health information to match the person’s learning needs,
  - avoiding the use of medical jargon,
  - providing access to health-care providers and peers for information, and
  - explaining information slowly and building the person’s knowledge progressively over time;
- Providing time for the person to absorb and process the new information; and
- Helping the person accept new ideas for adopting the skills and actions (to the extent they are able) that will allow them to self-manage their care

(Conway et al., 2006; Foster et al., 2013; Frampton et al., 2008; RNAO, 2012b; Saint Elizabeth, 2011; Widger et al., 2009).

Effective communication on the part of health-care providers is critical when providing information and education aimed at promoting the person’s ability to self-manage care (McCance et al., 2011; McCormack & McCance, 2006; Saint Elizabeth, 2011). Nurses should tailor strategies, such as coaching and educational materials, to meet the person’s characteristics (e.g., culture, health literacy, and language level) and learning preferences (e.g., written, verbal, visual, and electronic forms) (Haywood, Marshall, & Fitzpatrick, 2006; National Voices, 2014d; RNAO, 2012b; Renzaho et al., 2013; Richards et al., 2007). All communication tools and strategies (e.g., teach back<sup>G</sup>) to support the person’s health literacy for self-management of care should be: (a) linked to the person’s priorities and needs for care, (b) in the person’s preferred form (e.g., written, verbal, visual, etc.), and (c) at the appropriate level and in the person’s preferred language (Foster et al., 2013; Johnson et al., 2008; National Voices, 2014b, 2014d; RNAO, 2002, 2006a, 2012b; Smith et al., 2011; Widger et al., 2009).



## 4.0 EVALUATION

### RECOMMENDATION 4.1:

Obtain feedback from the person to determine the person's satisfaction with care and whether the care delivered was person- and family-centred.

Level of Evidence = Ia

### Discussion of Evidence:

An evaluation of care must start from the perspective of the person receiving care. Systematic reviews of the literature propose that members of the health-care team should seek feedback from the person regarding their level of satisfaction with care in order to monitor the outcomes of person- and family-centred care (Duncan, Best, & Hagen, 2010; National Ageing Research Institute, 2006; NICE, 2012, 2014; Robinson et al., 2008). Health-care providers should provide the person with “what to expect” information when delivering care so that the person can monitor and evaluate whether or not the expectations were met. Evaluation based on the person's own experience is the best way to evaluate the care provided and to determine what could be done to improve the delivery of care. This can be accomplished by holding discussions in a manner that encourages the person to express their needs and provide ongoing feedback on care (NICE, 2012, 2014).

The literature reports no global measure for satisfaction with person- and family-centred care. However, measuring common attributes of the concept is one solution (Dunst, Trivette, & Hamby, 2007; Hobbs, 2009; Holmstrom & Roing, 2010; Kitson et al., 2013; Mikkelsen & Frederiksen, 2011; Morgan & Yoder, 2012; National Ageing Research Institute, 2006; Pelzang, 2010; Robinson et al., 2008; Slater, 2006; The Johns Hopkins University Evidence-based Practice Center, 2012). Therefore, to evaluate the care provided, health-care providers should obtain and monitor ongoing feedback from the person to determine whether episodes of care contained the following attributes of person- and family-centred care:

- The person was treated as a partner within the therapeutic relationship (CNO, 2013b; Holmstrom & Roing, 2010; Mikkelsen & Frederiksen, 2011; National Ageing Research Institute, 2006; RNAO, 2002, 2006a, 2006b).
- There was respectful, truthful, and clear communication between health-care providers and the person (Holmstrom & Roing, 2010; National Ageing Research Institute, 2006; Pelzang, 2010).
- The person felt safe, had their fears and concerns addressed, did not feel rushed through the episode of care, and the health-care providers spent enough time with them (Foster et al., 2013; Widger et al., 2009).
- Health-care providers delivered quality care and services to meet the person's needs as a whole person, not just the needs dictated by their disease or illness (Holmstrom & Roing, 2010; Morgan & Yoder, 2012; National Ageing Research Institute, 2006; Pelzang, 2010; Slater, 2006).
- The person was an active participant in making decisions and tailoring their health care with health-care providers (shared the responsibility), taking into consideration their beliefs, values, culture, language, preferences for care, and life circumstances (Morgan & Yoder, 2012; National Ageing Research Institute, 2006; Robinson et al., 2008; Santen & Hemphill, 2011).
- Health-care providers discussed evidence-based practices and information with the person in a way that helped the person understand the options for care and enabled them to make a final decision on their preferred option(s) that met their goals and life context (i.e., informed consent<sup>G</sup> for care and treatment) (Holmstrom & Roing, 2010; Morgan & Yoder, 2012; National Ageing Research Institute, 2006; NICE, 2012, 2014; Pelzang, 2010; Simm et al., 2011).

It is important to obtain ongoing feedback from the person about what aspects of care are important to them. A review of the literature reported that nurses perceived their psychological skills as being more important (e.g., ability to provide comfort, anticipate the person's care needs, and build trusting relationships), whereas the person most valued the nurses' competence (technical skills and behaviours in nursing activities) and their ability to follow through on care (NICE, 2014). However, overall satisfaction with care was linked to nurses' warmth rather than their competence.

Collaboration between health-care providers and the person should be evaluated from the beginning to the end of the partnership (Shaller, 2007). Monitoring and obtaining timely and ongoing feedback on the effectiveness of collaboration among all participants in the relationship during the processes of care helps to establish an individualized plan of care, assists with determining the effectiveness of care strategies, facilitates the identification of gaps or barriers to care, and promotes the establishment of new directions for care to optimize clinical outcomes and improve the person's satisfaction and experience with health care and services.

To continually improve the quality of health services from the person's perspective, any information received from the person regarding gaps in care should be shared with the health-care team to provide them with the opportunity to improve the delivery of their services (Frampton et al., 2008; Saint Elizabeth, 2011). Therefore, obtaining feedback on the experience of care should be intentional and daily, during real time and documented. There should be demonstrated evidence that all feedback is being put to good use by the health-care team to improve the delivery of care to the person and not just used retrospectively after discharge from health services or at the end of an episode of care.



# Education Recommendations

## 5.0 EDUCATION

### RECOMMENDATION 5.1:

Educate health-care providers at a minimum on the following attributes of person- and family-centred care to improve the person's clinical outcomes and satisfaction with care:

- 1) Empowerment;
- 2) Communication; and
- 3) Shared decision making.

Level of Evidence = Ia

### Discussion of Evidence:

According to a systematic review of the literature, health-care providers who receive education on empowerment, communication, and shared decision making (skills and processes) have an increased ability to deliver person- and family-centred care (McMillan et al., 2013; Saint Elizabeth, 2011). The literature reports that this education improves the person's clinical outcomes and increases their satisfaction with and their perception of the quality of care (ACSQHC, 2011; Frampton et al., 2008; McCormack & McCance, 2010; McMillan et al., 2013; Saint Elizabeth, 2011).

Health-care providers should participate in professional development opportunities that support the development of their knowledge and ability to apply the following person- and family-centred-care attributes in practice:

- Establishing therapeutic relationships and empowering partnerships based on trust, sympathetic presence, and respect;
- Using effective verbal and non-verbal communication that is complete, unbiased, and affirming;
- Facilitating the timing and continuity of care;
- Addressing the whole person's needs and priorities for care, not just their disease;
- Incorporating the person's knowledge, values, beliefs, and cultural background into the planning and delivery of care;
- Collaborating with the person and promoting their involvement in care through shared decision making; and
- Providing free-flowing information

(CNO 2013b; College of Registered Nurses of Manitoba, 2013; Foster et al., 2013; Hobbs, 2009; Holmstrom & Roing, 2010; Kitson et al., 2013; Mikkelsen & Frederiksen, 2011; Morgan & Yoder, 2012; National Ageing Research Institute, 2006; NICE, 2012, 2014; RNAO, 2002, 2006a, 2006b, 2007; Robinson et al., 2008; Simm et al., 2011; Slater, 2006).

It is crucial that interprofessional team members develop and nurture strong partnerships with the person and their family to establish appropriate health care and services. Developing this strong partnership requires skills for managing conflict. Continuing professional development for nurses and other health-care providers should also include education on effective conflict resolution, interpersonal communication, and self-awareness for enhancing emotional intelligence and the ability to manage conflict (RNAO, 2012b).

**RECOMMENDATION 5.2:**

Educational institutions incorporate this Guideline into the curricula for nurses and, as appropriate, for other health-care providers.

Level of Evidence = V

## Discussion of Evidence:

Integrating this Guideline into the curricula for nurses and other health-care providers will ensure foundational learning regarding the evidence-based practices associated with person- and family-centred care. It is important for students of nursing and other allied health professionals to have a clear understanding of what person- and family-centred care is, and to recognize that the partnership they establish with the person affects the person's experience of health, their perceptions of the quality and effectiveness of the services they receive, and their satisfaction with those services. Approaches aimed at developing student knowledge and skills in person- and family-centred care should: (1) target clinical experience; (2) involve the person in student learning; and (3) use multiple learning strategies (Conway et al., 2006; RNAO, 2002, 2006a).

### Clinical Experience

Students should be given the opportunity to learn about person- and family-centred-care practices in clinical environments. Students' skill development should include engaging in conversations with the person to learn about their experiences of health and health care. Clinical experience can go beyond direct engagement. As a learning exercise, students should have an opportunity to observe health-care providers practicing person- and family-centred care in organizational settings (Johnson et al., 2008; RNAO, 2002, 2006a; Saint Elizabeth, 2011).

### Involving the Person in Student Learning

The literature supports the person telling their stories to students to support their education on person- and family-centred care (Johnson et al., 2008). This storytelling promotes student insight into the person's lived experience with care and the services delivered within the health system.

### Multiple Learning Strategies

Multiple learning strategies should be used to introduce best practices associated with person- and family-centred care into curricula for nurses and other health-care providers. These should include journaling as a tool for reflective practice<sup>G</sup>, role-playing, simulation, computer-based programs, coaching, workshops, and videos (Conway et al., 2006; McCormack & McCance, 2010; RNAO, 2002, 2006a).

# System, Organization and Policy Recommendations

## 6.0 SYSTEM, ORGANIZATION AND POLICY

### RECOMMENDATION 6.1:

Create an organizational culture that exemplifies its commitment to person- and family-centred care by:

- 1) Demonstrating leadership and commitment to this approach to care;
- 2) Involving the person in co-designing health programs and services; and
- 3) Building healthy work environments for all health-care providers.

Level of Evidence = V

### Discussion of Evidence:

Organizations are responsible for creating environments that exemplify the value of respectful person- and family-centred-care partnerships and practices (Frampton et al., 2008; Shaller, 2007). To implement person- and family-centred care, organizations must believe in and value this approach to the delivery of health care and services. Organizations demonstrate this by creating environments that enable health-care providers to practise in a person- and family-centred way using their knowledge, skills, and abilities (de Silva, 2014; Frampton et al., 2008; International Alliance of Patients' Organizations, 2012; Manley et al., 2011; Shaller, 2007). Organizations should create a culture that is focused on providing person- and family-centred care by: (1) demonstrating leadership and commitment to this approach to care, (2) involving the person in co-designing health programs and services, and (3) building healthy work environments for health-care providers.

### Demonstrating Leadership and Commitment

Senior leaders are responsible for setting priorities and directions based on the mission and vision for their organization. Therefore, senior leaders must commit to embedding the attributes of person- and family-centred care into their organizational culture by:

- Including the attributes of the concept into the mission, vision, value statements, and strategies of the organization to demonstrate a commitment to person- and family-centred care;
- Designing and establishing a charter of rights for individuals accessing health care and services (refer to [Appendix F](#) for common themes in patients' charters of rights);
- Being inspiring and leading through example by modelling person- and family-centred behaviours in encounters with staff;

- Ensuring resources are available for:
  - the ongoing development (educating and mentoring) of staff in person- and family-centred care, to improve their skills and their ability to deliver such care in practice, and
  - the education of users of the health system, to ensure meaningful participation on committees to design person- and family-centred care and services;
- Monitoring, collecting, and evaluating data on individuals' experience of health care and services, and using these perspective to drive organizational improvements; and
- Incorporating person- and family-centred-care expectations into the organization's system designs (policy reviews, development of procedures, hiring practices, and performance reviews of staff)

(ACSQHC, 2011; Alzheimer Society, 2011; CMA, 2010; CMA & CNA, 2011; Ciufu et al., 2011; Committee on Hospital Care & Institute for Patient- and Family-Centred Care, 2012; Conway et al., 2006; Frampton et al., 2008; Harvey Picker Centre of Innovation and Applied Research in Long-Term Care, 2013; Hernandez, Conrad, Marcus-Smith, Reed, & Watts, 2013; Johnson et al., 2008; KPMG, 2009; MacKean et al., 2012; Manley et al., 2011; McCance et al., 2011; McCormack & McCance, 2006; Pelzang, 2010; RNAO, 2002, 2006a, 2013b; Shaller, 2007).

### Involving the Person

It is important to seek the person's personal stories about their experience of care and involve them as active partners in meaningful roles and on committees within the organization to improve the quality of health services (ACSQHC, 2011; American Hospital Association & Institute for Patient- and Family-Centred Care, 2004; CMA, 2010; Frampton et al., 2008; KPMG, 2009; Lewis, 2009). Doing this ensures that individuals' perspectives on health care and service are central to health program planning, quality improvement, and system design (Frampton et al., 2008; NICE, 2012, 2014; WHO, 2007a, 2007b). Engagement opportunities include: having a role on the board of trustees, advisory panels, family and resident councils, and in staff hiring and orientation; and participating on key committees such as quality improvement, and in strategic planning for program and facility design, policy, education, and research (Frampton et al., 2008; Saint Elizabeth, 2011).

### Building Healthy Work Environments

Sustaining a person- and family-centred approach to care delivery requires all staff to work in a supportive environment (ACSQHC, 2011; Frampton et al., 2008; Harvey Picker Centre of Innovation and Applied Research in Long-Term Care, 2013; Manley et al., 2011; RNAO, 2002, 2006a, 2008, 2013a, 2013b; Saint Elizabeth, 2011; Shaller, 2007). In order to deliver person- and family-centred care, staff must feel valued and respected, be genuinely cared for (including emotional support), and have their achievements recognized and celebrated by leaders when they partner effectively with the person and personalize care (Frampton et al., 2008; Hernandez et al., 2013; MacKean et al., 2012; McCance et al., 2011; Pelzang, 2010; Saint Elizabeth, 2011; Shaller, 2007). Leadership should promote shared governance and allow for input and feedback from all staff (including volunteers) related to the quality, design, and workflow of care and services (Alzheimer Society, 2011; Conway et al., 2006; Frampton et al., 2008; Morgan & Yoder, 2012; National Ageing Research Institute, 2006; Shaller, 2007).

Lack of autonomy for health-care providers in practice within an organization is a barrier to their ability to deliver person- and family-centred care, and organizations must establish policies and procedures that promote the autonomy of staff to deliver such care (National Ageing Research Institute, 2006). Organizations must prepare and support staff for partnering and engaging with the person, their family and caregivers and other health-care providers in empowering relationships. While policies and procedures can be implemented to promote professional autonomy, improve the quality and continuity of care, help disseminate evidence-based practices, and inform staff of their role and responsibilities, they need to be flexible to allow staff to practise in person- and family-centred ways (e.g., allowing the person's pet to visit them in the hospital while taking into consideration infection control concerns)

(American Hospital Association & Institute for Patient- and Family-Centred Care, 2004; Committee on Hospital Care & Institute for Patient- and Family-Centred Care, 2012; Manley et al., 2011). Furthermore, policies and procedures should be established in partnership with the person and staff and physicians to ensure that all perspectives are represented (e.g., a health setting's policy on visiting hours should be created based on input from the consumers of their health services and the organization's staff) (Ciuffo et al., 2011; Morgan & Yoder, 2012).

### RECOMMENDATION 6.2:

Design an environment that demonstrably improves the person's experience of health care by:

- 1) Creating healing environments;
- 2) Being flexible and partnering to personalize care routines;
- 3) Improving access to care and services;
- 4) Enhancing the continuity and coordination of care and services during transitions; and
- 5) Providing continuity of caregivers.

Level of Evidence = V

## Discussion of Evidence:

Organizations should design health-care settings to include features that are known to affect individuals' experience and satisfaction with the delivery of health-care services. This includes: (1) creating healing environments; (2) being flexible and partnering to personalize care routines; (3) improving access to care and services; (4) enhancing the continuity in and coordination of care and services during transitions; and (5) promoting the continuity of caregivers (ACSQHC, 2011; Frampton et al., 2008; Harvey Picker Centre of Innovation and Applied Research in Long-Term Care, 2013; RNAO, 2002, 2006a; Saint Elizabeth, 2011).

### Creating Healing Environments

An organization's environment (physical space, sights, smells, and sounds) plays an important role in the person's experience and, later, their recollection of health care (Frampton et al., 2008; RNAO, 2002, 2006a; Shaller, 2007). The person's immediate physical setting should be customized based on input from the person regarding features that will support healing. For example, personal items and pictures can create a more home-like environment and help the person maintain their sense of identity and connection to family during their stay (RNAO, 2002, 2006a). To improve the person's experience of health care and services, organizations should actively partner with the person to improve or redesign aspects of the environment that are frustrating or that present challenges – for example, labelling entrances or putting up signs to assist with directions, reducing physical and other barriers to staff (e.g., using partitioned nursing stations and providing nametags for staff), improving the design of hospital gowns, having a scent free or scent reduction policy to avoid allergic reactions, using wall colours and furniture to make the setting more like home than an institution, and reducing hallway clutter (equipment) (ACSQHC, 2011; Frampton et al., 2008; Johnson et al., 2008; Saint Elizabeth, 2011).

## Being Flexible and Partnering to Personalize Care Routines

Accessing the health system for care and services can be dehumanizing and confusing (Alzheimer Society, 2011; Gottlieb, Gottlieb, & Shamian, 2012). Engaging the person in planning and decision making for their health care helps them maintain their autonomy and a degree of independence (Alzheimer Society, 2011; Brownie & Nancarrow, 2013; Frampton et al., 2008; RNAO, 2002, 2006a; Say et al., 2006). Some areas of care delivery that can be personalized within organizations include: food options, timing of meals, scheduling of procedures, de-escalation processes (i.e., to avoid application of physical or chemical restraints), and provision of meaningful activities (e.g., occupational and recreation therapy, music, and painting) (Alzheimer Society, 2011; Frampton et al., 2008).

## Improving Access to Care and Services

Individuals require timely access to health care and services. Therefore, organizations need to improve access in areas typically considered problematic by persons using the health system, such as the location of services, transportation, parking, scheduling, availability of appointments, wait times, access to primary care, and referrals to specialists (CMA, 2010; CMA & CNA, 2011; KPMG, 2009; Lewis, 2009; National Ageing Research Institute, 2006; National Research Corporation Canada, 2014; RNAO, 2012a, 2014b).

Staff shortages resulting in insufficient time spent with the person, inconsistent assignments, and large caseloads are significant barriers to health-care providers' ability to deliver person- and family-centred care (Alzheimer Society, 2011; Foster et al., 2010; National Ageing Research Institute, 2006; Pelzang, 2010). Organizations should improve individuals' access to members of the health-care team by designing a model of care that encourages them to spend more time discussing care with the person. This helps ensure that the person has time to clarify and process the information they require to make decisions about their care (Cancer Journey Portfolio, 2012; Frampton et al., 2008; National Research Corporation Canada, 2014; National Voices, 2014a, 2014b, 2014e; RNAO, 2002, 2006a; Tzelepis et al., 2014).

When discussing options for care, health-care providers should devote more time to: (a) listening to the person's stories and partnering with them to determine their care needs based on their preferences, values, and beliefs; and (b) evaluating the outcomes and next steps in care (Frampton et al., 2008; RNAO, 2002, 2006a, 2014a). Providing the person with access to their health record, the organization's medical libraries, and social technologies (e.g., information kiosks and computers with internet access) assists with the transfer of health information to the person for their education (Lewis, 2009; RNAO, 2013a). Health-care providers can then spend time discussing the materials the person accessed to improve the person's health literacy for self-management of care and decision making (Johnson et al., 2008; National Voices, 2014b; Saint Elizabeth, 2011; Shaller, 2007).

## Enhancing Continuity and Coordination During Transitions

Effective coordination of health services for the person within, between, and across settings and providers is critical to continuity of care, and impacts the person's safety and experience of care (Committee on Hospital Care & Institute for Patient- and Family-Centred Care, 2012; Frampton et al., 2008; Harvey Picker Centre of Innovation and Applied Research in Long-Term Care, 2013; National Research Corporation Canada, 2014; National Voices, 2014a; RNAO, 2014a; Saint Elizabeth, 2011). Lack of effective coordination of services across the interprofessional team can impact the primary health-care provider's ability to see what care is required for the whole person (Pelzang, 2010; RNAO, 2013a, 2014a). Organizations must establish systems (transition planning processes, system navigators, and follow-up procedures) to support the ability of members of the interprofessional team to coordinate and personalize care for individuals undergoing care transitions<sup>G</sup> (Cancer Journey Portfolio, 2012; Committee on



Hospital Care & Institute for Patient- and Family-Centred Care, 2012; Frampton et al., 2008; Harun, Harrison, & Young, 2013; Johnson et al., 2008; Murray et al., 2006; National Voices, 2014a; RNAO, 2014a; Saint Elizabeth, 2011; Tzelepis et al., 2014). An integrated health system assists members of the interprofessional team to work in partnership with the person across multiple settings to plan care and services and maintain continuity of care during transitions (Alzheimer Society, 2011; Committee on Hospital Care & Institute for Patient- and Family-Centred Care, 2012; Foster et al., 2010; MacKean et al., 2012; National Research Corporation Canada, 2014; RNAO, 2013a, 2014a).

During care transitions, the use of health information technologies improves the quality, safety, and communication of care needs (Dagnone, 2009; Frampton et al., 2008; KPMG, 2009). The electronic health record supports a person- and family-centred approach to care because it enhances the communication of information, such as: the person's beliefs, values, goals, preferences (based on diagnosis), and decisions on care interventions (medication, treatment); outcomes (tests, reports, person's response to treatment); and follow-up requirements necessary for coordinated and integrated care across health settings and providers (KPMG, 2009; RNAO, 2014a; Saint Elizabeth, 2011; Shaller, 2007; The Johns Hopkins University Evidence-based Practice Center, 2012). Leadership must also establish policies and procedures that enable individuals to access their electronic health record (Frampton et al., 2008).

### Providing Continuity of Caregivers

Continuity of caregivers is fundamental to: continuity of care; building respectful partnerships with the person over time; coming to know the whole person for the purposes of personalizing their health care; and improving the experience of care (KPMG, 2009; Manley et al., 2011; NICE, 2012, 2014; RNAO, 2002, 2006a). Creating an environment that enhances the continuity of care has the potential to improve the person's experience of care, decrease use of health services and costs (National Voices, 2014a). Organizations should strive to provide continuity of caregivers so the person experiences consistent therapeutic relationships that build their sense of safety, belonging and partnership with health-care providers across the continuum of their care (Cancer Journey Portfolio, 2012; International Alliance of Patients' Organizations, 2012; Irwin & Richardson, 2006; McCance et al., 2011; RNAO, 2002, 2006a).

#### RECOMMENDATION 6.3:

Collect continuous feedback from the person to determine whether their experience with health care and services was person- and family-centred, and utilize this feedback to make improvements at all levels of the health system.

Level of Evidence = III

### Discussion of Evidence:

In Canada and other countries, transformation initiatives are underway to improve the person's experience with the care and services delivered within the health system (ACSQHC, 2011; Baker, Bankart, & Murtagh, 2009; Lewis, 2009; National Voices, 2014a). The person must be kept central to quality improvements (Conway et al., 2006; Johnson et al., 2008; WHO, 2007a). Promoting partnerships between the person and health-care organizations to improve the design and delivery of health-system services and population health can occur on an individual basis or across groups of people and their communities. For a summary of recent initiatives and examples, refer to the discussion under Background.

The literature reports that person- and family-centred care improves the person's adoption of healthy behaviours, functional status, psychosocial well-being, ability to self-manage care, continuity of care, and safety, and decreases utilization of the health system (Gumpert & Dill, 2013; Hoff, Weller, & Depuccio, 2012). Organizations must use multiple strategies to design and improve their programs from the perspective of the person to enhance the level of satisfaction with the delivery of care and services (Frampton et al., 2008; Hernandez et al., 2013; National Ageing Research Institute, 2006). Therefore, organizations must seek continuous feedback from individuals regarding their experiences with health services and must ensure that they have met their priorities for care (e.g., respect, timely access to care and services, caring environments, communication and partnering for decisions on health, continuity and coordination of care, communication, and cultural competency) (Committee on Hospital Care & Institute for Patient- and Family-Centred Care, 2012; Frampton et al., 2008; Greene et al., 2012; Hernandez et al., 2013; National Research Corporation Canada, 2014; National Voices, 2014a; 2014b, 2014d, 2014e; RNAO, 2002, 2006a). Obtaining continuous feedback, reflecting and taking action for quality improvement helps organizations maintain their focus on the person and demonstrate the feedback was utilized to improve aspects of service delivery (continuity of care and staff retention) known to impact on the experience of care (Committee on Hospital Care & Institute for Patient- and Family-Centred Care, 2012; Frampton et al., 2008; National Ageing Research Institute, 2006).

There is no single tool or approach available to measure all elements of person- and family-centred care (de Silva, 2014; Edvardsson & Innes, 2010; Frampton et al., 2008). Therefore, to measure the experience of care from the perspective of the person and staff, organizations should use multiple strategies (e.g., case studies, observation, interviews, and small group discussions) and evidence-based evaluation tools (e.g., questionnaires and surveys) (Cancer Journey Portfolio, 2012; de Silva, 2014; Frampton et al., 2008; Richmond PRA, 2013). **Appendix E** contains a list of organizations with tools for evaluating person- and family-centred care. The person must be asked if they wish to participate in an evaluation of their care and asked what their preferred method of evaluation is (e.g., telephone, survey, or other) (Committee on Hospital Care & Institute for Patient- and Family-Centred Care, 2012; Manley et al., 2011).

Organizations should select evaluation measures in partnership with the populations they serve as well as their staff, to ensure consensus<sup>G</sup> on elements associated with person- and family-centred-care practices (Greene et al., 2012; Health Education and Training Institute, 2012; International Alliance of Patients' Organizations, 2012; Richmond PRA, 2013). Organizations should also consider the timing and frequency of evaluations related to performance or gaps in their health care and services (de Silva, 2014). Evaluations must be undertaken prior to and following implementation of person- and family-centred-care practices (Ambresin et al., 2013; de Silva, 2014; Frampton et al., 2008). For example, if staff were to attend education sessions on the elements of person- and family-centred care, evaluations prior to and following education should be conducted to determine initial baseline knowledge and to measure improvement following education sessions.

**RECOMMENDATION 6.4:**

Government agencies and regulatory bodies must monitor, measure, and utilize information from organizations regarding the person's experience of health care to improve health-system performance.

**Level of Evidence = Ia**

### Discussion of Evidence:

Government health-care agencies and regulatory bodies have an important role to play in monitoring and measuring the information from organizations on individuals' experience of health, and using this information to improve health-system performance (delivery of care and services) (Ambresin et al., 2013; Hernandez et al., 2013). Legislation and regulations create organizational accountability for the quality and experience of health care and services in the populations they serve (Hernandez et al., 2013).

For example, the Ontario government passed the *Excellent Care for All Act, 2010* (2010) (ECFAA) to regulate the way in which care and services are delivered throughout the province's health system. Recognizing that the experience of the person is an important part of health-care quality, the ECFAA aims to ensure that the person is at the centre of the health system, that decisions on care are based on the best available evidence, and that improvement focuses on the quality of health care and service delivery. The Preamble to the ECFAA outlines the beliefs and commitments of the people of Ontario and their government with respect to health care, including their commitment to "ensuring that health care organizations are responsive and accountable to the public, and focused on creating a positive patient experience and delivering high quality health care." The provisions of the ECFAA set out various requirements for health-care organizations subject to the Act, such as: establishing quality committees to report on relevant issues (ss. 3-4); conducting surveys of persons who have accessed services, caregivers, and staff (s. 5); establishing a patient relations process to improve the experience of patients (s. 6); and developing and making available to the public annual quality improvement plans (s. 8). Such information can be used to improve overall health-system performance.

Government agencies and regulatory bodies must monitor the performance of all health settings to ensure that improving the overall quality of care and services delivered within the health system actually enhances the experience of health care for individuals (Corlett & Twycross, 2006; Hernandez et al., 2013).

# Research Gaps and Future Implications

The RNAO expert panel, in reviewing the evidence for this Guideline, identified the priority areas for research set out in Table 7. They are broadly categorized into practice, outcome, and health-system research.

**Table 7. Priority Practice, Outcome, and Health-System Research Areas**

CATEGORY	PRIORITY RESEARCH AREA
Practice research	Person- and family-centred-care practices that optimize health outcomes (illness and wellness)
	Standardized terms and definitions of the concept and components that constitute person- and family-centred care
	Aspects of the health-care partnership (between health-care providers and the person) that impact health outcomes
	Role of nursing in the delivery of person- and family-centred care
	Implications of person- and family-centred initiatives on interprofessional-team practices
	Effective health-care-provider practices that improve treatment participation in diverse populations
	Evidence-based decision aids validated for age and population
	Effective techniques that promote a person- and family-centred approach when using technology for consultations (e.g., Ontario Telehealth Network)
	Interventions by health-care providers to enhance the person’s involvement in making decisions for health care
	Effect of education on health-care providers’ capacity to practise person- and family-centred care
	Effective interventions that enhance health-care providers’ cultural competency
	Effective communication practices that facilitate parents’ ethical decision making with respect to care for their children
	Aspects of care during a child’s hospitalization in which parents can be involved to enhance their participation in care
Effective information technology applications that promote person- and family-centred care	

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CATEGORY	PRIORITY RESEARCH AREA
Outcome research	Effective health-care transformation initiatives (e.g., marketing and websites) to improve health (prevention and promotion)
	Impacts of a person-centred model of care on the person, organization, and health system
	Impact of shared decision making on health outcomes
	Impact of the person’s active participation in decision making on the person’s health and clinical outcomes
	Impact of information technology applications on the person’s health and on health-care providers’ practice
	Impact of staffing practices on a person’s clinical outcomes and satisfaction with care
	Effect of education on health-care providers’ use of person- and family-centred-care practices
	Effect of supportive person- and family-centred environments on the person’s health and satisfaction with care
	Impact of engaging persons and their families in the development and implementation of Human Resource strategies for staff (e.g., engagement and retention) on the person’s satisfaction with care
Health-system research	Specific person- and family-centred-care behaviours (health-care provider roles and responsibilities) that improve quality of care at all levels of the health-care system (micro, meso, and macro)
	Antecedents and preconditions that build and sustain person- and family-centred-care cultures at all levels of the health system
	Impact of health-care transformation initiatives (e.g., marketing and websites) on person and family involvement in health-system reform
	Organization and government policies that improve person and family involvement in health research (design, implementation and evaluation of research studies) and system reform
	Universal standardized indicators to target aspects of person- and family-centred care that improve clinical outcomes and health-system performance
	Short- and long-term impacts of person- and family-centred care on health and health-system utilization
	Impacts of improving health-system access and navigation on clinical and system-level outcomes

The above table, though not exhaustive, is an attempt to identify and prioritize the research needed with respect to person- and family-centred care. Many of the recommendations in this Guideline are based on quantitative and qualitative research evidence; others are based on RNAO expert panel opinion. Further substantive research is required to validate some of these recommendations. Increasing the research evidence will lead to improved person- and family-centred-care practices.

## Implementation Strategies

Implementing guidelines at the point of care is multi-faceted and challenging; it takes more than awareness and distribution of guidelines to get people to change how they practice. Guidelines must be adapted for each practice setting in a systematic and participatory way, to ensure recommendations fit the local context (Harrison, Graham, Fervers, & Hoek, 2013). The RNAO *Toolkit: Implementation of Best Practice Guidelines* (2012d) provides an evidence-informed process for doing this (see [Appendix G](#)).

The *Toolkit* is based on emerging evidence that successful uptake of best practice in health care is more likely when:

- Leaders at all levels are committed to supporting guideline implementation;
- Guidelines are selected for implementation through a systematic, participatory process;
- Stakeholders for whom the guidelines are relevant are identified and engaged in the implementation;
- Environmental readiness for implementing guidelines is assessed;
- The guideline is tailored to the local context;
- Barriers and facilitators to using the guideline are assessed and addressed;
- Interventions to promote use of the guideline are selected;
- Use of the guideline is systematically monitored and sustained;
- Evaluation of the guideline’s impact is embedded in the process; and
- There are adequate resources to complete all aspects of the implementation.

The *Toolkit* uses the “Knowledge-to-Action” framework (Straus, Tetroe, Graham, Zwarenstein, & Bhattacharyya, 2009) to demonstrate the process steps required for knowledge inquiry and synthesis. It also guides the adaptation of the new knowledge to the local context and implementation. This framework suggests identifying and using knowledge tools, such as guidelines, to identify gaps and to begin the process of tailoring the new knowledge to local settings.

RNAO is committed to widespread deployment and implementation of our Best Practice Guidelines (BPGs). We use a coordinated approach to dissemination, incorporating a variety of strategies, including: 1) the Nursing Best Practice Champion Network<sup>®</sup>, which develops the capacity of individual nurses to foster awareness, engagement, and adoption of BPGs; 2) nursing order sets<sup>G</sup> which provide clear, concise, actionable intervention statements derived from the BPGs’ practice recommendations that can be readily embedded within electronic medical records, but may also be used in paper-based or hybrid environments; and 3) the Best Practice Spotlight Organization<sup>®</sup> (BPSO<sup>®</sup>) designation, which supports implementation at the organization and system levels. BPSOs<sup>®</sup> focus on developing evidence-based cultures with the specific mandate to implement, evaluate, and sustain multiple RNAO BPGs. In addition, we offer capacity-building learning institutes on specific BPGs and their implementation annually (RNAO, 2012d).

Information about our implementation strategies can be found at:

- RNAO Best Practice Champions Network<sup>®</sup>: <http://RNAO.ca/bpg/get-involved/champions>
- RNAO Nursing Order Sets: nursing order sets: <http://rnao.ca/bpg/initiatives/nursing-order-sets>
- RNAO Best Practice Spotlight Organizations<sup>®</sup>: <http://RNAO.ca/bpg/bpso>
- RNAO capacity-building learning institutes and other professional development opportunities: <http://RNAO.ca/events>

# Evaluating and Monitoring this Guideline

As you implement the recommendations in this Guideline, we ask you to consider how you will monitor and evaluate its implementation and impact.

Table 8 is based on a framework outlined in the RNAO’s *Toolkit: Implementation of Best Practice Guidelines* (2012d) and illustrates some specific indicators for monitoring and evaluating implementation of this Guideline.

**Table 8. Structure, Process, and Outcome Indicators for Monitoring and Evaluating This Guideline**

TYPE OF INDICATOR		
STRUCTURE	PROCESS	OUTCOME
<p>These indicators refer to the supports and resources required for a health system, health service organization or academic institution that enable the successful implementation of the Guideline, <i>Person- and Family-Centred Care</i>.</p>	<p>These indicators evaluate whether best practices directed at the education, training, and practice of health-care professionals to improve person- and family-centred care have been implemented.</p>	<p>These indicators evaluate the impact of implementing the Guideline recommendations on health-care organizations, health-care professionals and client outcomes.</p>
<p>Availability of system structures to promote the person as the central focus of health service delivery and support their engagement in health-system improvement (e.g., presence of legislation such as Excellent Care For All Act and Local Health Integration Networks).</p> <p>Availability of integrated system-wide policies consistent with best practices and guideline recommendations for supporting a person- and family-centred care health system.</p>	<p>Percentage of persons who participate in undergraduate student education by telling their stories and experiences with health care and services.</p> <p>Percentage of nurses who completed an annual performance review.</p> <p>Percentage of newly hired nurses who attended an orientation session related to person- and family-centred care best practices.</p>	<p>Demonstrated cost-effectiveness of person- and family-centred care practices (e.g., continuity in caregivers, availability of decision aids and education materials, and electronic health record and documentation tools).</p> <p>Percentage of health-care providers (e.g., nurses) who report satisfaction with the education and training provided to enhance their knowledge and skills related to person- and family-centred- practices (e.g., shared decision-making, empowerment, effective communication and conflict management).</p> <p>Percentage of nurses who demonstrate self-reflection related to the delivery of person- and family-centred care in most recent performance evaluation.</p>

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TYPE OF INDICATOR		
STRUCTURE	PROCESS	OUTCOME
<p>Availability of system-wide standardized measures to monitor the person’s experience of care.</p> <p>Organizations establish person- and family-centred care as a strategic priority and integrate the concept’s attributes into their mission, vision, values, policy and procedures, staff hiring, orientation programs and service design.</p> <p>Organizations have processes in place that ensures input from the person and their community and staff in planning and evaluating programs and services.</p> <p>Organizations adopt a model of care that promotes coordination of care and continuity of health-care providers.</p> <p>Availability of educational resources (e.g., in multiple formats: written, verbal, video and language) and decision aides within an organization to increase a person’s health literacy and ability to make decisions on their health care.</p> <p>Availability of documentation tools that support person- and family-centred-care practices between health-care team members and the person.</p>	<p>*Percentage of care plans outlining the person’s beliefs, values, culture, goals and preferences to ensure personalized health services.</p> <p>Percentage of persons who were given free flowing and unbiased information in a form and language they preferred to improve their health literacy.</p> <p>*Percentage of persons asked or surveyed by health-care providers about their satisfaction with, and experience of health care.</p>	<p>Percentage of health-care providers attending committees and councils as active partners for service improvements or program redesign (e.g., initiatives for healthy work environments).</p> <p>Percentage of staffing schedules that demonstrate health-care providers scheduled to care for the same person over time.</p> <p>Percentage of persons who experienced poor coordination of care during transitions resulting in increased service utilization, unexpected readmission or adverse event.</p> <p>Percentage of boards, councils and committees with persons as advisors to assist with reforming or improving the delivery of health care at the local, provincial and federal government level.</p> <p>*Percentage of persons reporting increased satisfaction with the experience of care pertaining to being:</p> <ul style="list-style-type: none"> <li>■ *treated with respect and courtesy (by nurses)</li> <li>■ treated as a whole person (biopsychosocial and spiritually) not just their disease or illness (holistic care)</li> <li>■ asked about family members they wish to include in their circle of care and the preferred level of involvement</li> <li>■ asked about their preferred level of active involvement in their care (planning, decision-making)</li> <li>■ asked about their priorities and goals for care and these preferences were integrated into the plan to personalize care (e.g., being asked preferences for visiting hours, food, timing of meals and personal care)</li> <li>■ *listened to (by nurses)</li> </ul>



TYPE OF INDICATOR		
STRUCTURE	PROCESS	OUTCOME
<p>Organizations’ annual performance reviews emphasize reflective practice and ongoing professional development to promote the use of person- and family-centred-care practices by all nursing staff.</p> <p>Availability of funding to promote a person- and family-centred-care culture.</p> <p>Structures are in place to facilitate the integration of theory and evidence based practices associated with person- and family-centred care into health-care providers’ program curricula (e.g., the person is involved in design of education programs to promote their experience of health care).</p>		<ul style="list-style-type: none"> <li>■ given enough time and information by nurses (*explained in a way they could understand) to make an informed decision on preferred options for care</li> <li>■ able to access and document in their health record</li> </ul> <p>Percentage of persons receiving health services who were satisfied with the way their health-care provider communicated (e.g., use of verbal and non-verbal communication) in promoting trust, being empowered to be involved in the planning of and make decisions for their health care).</p> <p>Percentage of persons demonstrating improved health literacy for self-managing their health and wellness.</p>

RECOMMENDATIONS

\*These process and outcome indicators have been taken from the NQuIRE® Data Dictionary for the RNAO BPG *Client Centred Care* (RNAO & Nursing and Healthcare Research Unit [Investén-isciii], 2012).

Other RNAO resources for the evaluation and monitoring of Best Practice Guidelines:

- Nursing Quality Indicators for Reporting and Evaluation® (NQuIRE®) were designed for RNAO’s Best Practice Spotlight Organizations® (BPSO®) to systematically monitor the progress and evaluate the outcomes of implementing RNAO best practice guidelines in their organizations. NQuIRE is the first international quality improvement initiative of its kind consisting of a database of quality indicators derived from recommendations of selected RNAO clinical Best Practice Guidelines. Please visit <http://rnao.ca/bpg/initiatives/nquire> for more information.
- Nursing order sets embedded within electronic medical records provide a mechanism for electronic data capture of process indicators. The ability to link structure and process indicators with specific client outcome indicators aids in determining the impact of BPG implementation on specific client health outcomes. Please visit <http://rnao.ca/ehealth/nursingordersets> for more information.

# Process for Update and Review of the Guideline

The Registered Nurses' Association of Ontario (RNAO) commits to updating its Best Practice Guidelines (BPG) as follows:

1. Each BPG will be reviewed by a team of specialists in the topic area every five years following publication of the previous edition.
2. RNAO International Affairs and Best Practice Guideline (IABPG) Centre staff regularly monitor for new systematic reviews, randomized controlled trials, and other relevant literature in the field.
3. Based on that monitoring, IABPG Centre staff may recommend an earlier revision period for a particular BPG. Appropriate consultation with members of the original expert panel and other specialists and experts in the field will help inform the decision to review and revise the BPG earlier than the targeted milestone.
4. Three months prior to the review milestone, IABPG Centre staff commence planning of the review by:
  - a) Inviting specialists in the field to participate on the expert panel. The panel will be composed of members from the original expert panel as well as other recommended specialists and experts.
  - b) Compiling feedback received and questions encountered during the implementation, including comments and experiences of BPSOs® and other implementation sites regarding their experiences.
  - c) Compiling new clinical best practice guidelines in the field and conducting a systematic review of the evidence.
  - d) Developing a detailed work plan with target dates and deliverables for developing a new edition of the BPG.
5. New editions of BPGs will be disseminated based on established structures and processes.



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## Appendix A: Glossary of Terms

**Analytical studies:** Analytical studies test hypotheses about exposure–outcome relationships. The investigators do not assign an intervention, exposure, or treatment but do measure the association between exposure and outcome over time, using a comparison group (Centers for Disease Control and Prevention [CDC], 2013). Analytical study designs include case-control studies and cohort studies.

**Case-control study:** A study that compares people with a specific disease or outcome of interest (cases) to people from the same population without that disease or outcome (controls) (The Cochrane Collaboration, 2005).

**Cohort study:** An observational study in which a defined group of people (the cohort) is followed over time either prospectively or retrospectively (The Cochrane Collaboration, 2005).

**Attitude:** The way a person looks and feels about something, which can be positive or negative (“Attitude,” 2003).

*See person-centred-care attitudes and behaviours*

**Autonomy:** The freedom to make decisions and choices for one’s life without the controlling influences of others and other restraining confinements (e.g., an inadequate understanding of a situation or an issue that prevents meaningful choice) (Beauchamp & Childress, 2009).

**Best practice guidelines:** Systematically developed statements to assist practitioner and client decisions about appropriate health care for specific clinical (practice) circumstances (Field & Lohr, 1990); also called *clinical practice guidelines*.

**Capacity:** In Ontario, under s. 4 of the *Health Care Consent Act, 1996* (1996), a person is considered capable of making decisions with respect to a treatment, admission to a care facility, or a personal assistance service if they understand the information relevant to making the decision and can appreciate any foreseeable consequences involved with making or not making the decision.

**Care transitions:** A set of actions designed to ensure the safe and effective coordination and continuity of care as individuals experience a change in health status, care needs, health-care providers, or location, within, between, or across settings (RNAO, 2014a).

**Circle of care:** This term includes all health-care providers such as physicians and other health-care-team members (e.g., RRTs, RNs, and other employees) who have a direct responsibility for providing care to the patient, as well as the patient, significant others identified by the patient to be involved in their care, and/or their substitute decision-maker (College of Respiratory Therapists of Ontario, 2013).

**Competencies:** The integrated knowledge, skills, abilities, attitudes, and judgment required to practise nursing safely and ethically in a designated role or setting (CNO, 2014b).

**Consensus:** A process for making policy decisions, not a scientific method for creating new knowledge. Consensus development makes the best use of available information, be that scientific data or the collective wisdom of the participants (Black et al., 1999).

**Controlled study:** A clinical trial in which the investigator assigns an intervention, exposure, or treatment to participants who are not randomly allocated to the experimental and comparison or control group (The Cochrane Collaboration, 2005).

**Culture:** Culture refers to the shared and learned values, beliefs, norms, and ways of life of an individual or a group. It influences thinking, decisions, and actions (CNO, 2013b).

**Decision aid:** Decision aids are tools that help provide structure in order to facilitate decision making, especially in situations where multiple reasonable options or scientific uncertainties exist and there does not seem to be a clear advantageous option. Decision aids assist in describing the available options, helping to clarify the potential benefits and harms of each so that the person can understand and make an informed decision based on what they value or consider important. Decision aids such as pamphlets, videos, and actual decision-making tools assist persons to participate in and direct care and treatment decisions with their health-care provider by:

- improving the person’s knowledge of available options so they are better informed to make decisions,
- helping the person establish clarity about what matters most to them, and
- assisting the patient to see the potential benefit(s) and harm(s) associated with each option realistically.

Decision aides do not replace, but supplement, health-care providers’ counseling about care, service, and treatment options when the person indicates they are ready to manage the decision. Decision aides help improve the process and the quality of a person’s decision making (Leise, 2013; RNAO, 2002, 2006a; Stacy et al., 2014).

**Decision-making process:** The steps a person goes through to make decisions about their care. The quality of the decision-making process can be determined by evaluating the process itself. This means asking the person making the decision to evaluate the following:

- Whether they received enough information (specialized knowledge) to make a decision;
- Whether the information was given without bias or an attempt to sway the person toward a particular option;
- Whether the information included an explanation of the benefit(s), harms(s), and scientific uncertainties, and whether alternative options were provided for consideration;
- Whether the person’s values and goals were considered;
- Whether the person was given enough time to make the decision; and
- Whether the person was included in the decision-making process to their preferred degree of participation

(Leise, 2013; RNAO, 2002, 2006a).

*See shared decision making*



**Descriptive studies:** Studies that generate hypotheses and describe characteristics of a sample of individuals at one point in time. The investigators do not assign an intervention, exposure, or treatment to test a hypothesis, but merely describe the who, where, or when in relation to an outcome (CDC, 2013; The Cochrane Collaboration, 2005). Descriptive study designs include cross-sectional studies.

Cross-sectional study: A study measuring the distribution of some characteristic(s) in a population at a particular point in time (also called a *survey*) (The Cochrane Collaboration, 2005).

**Determinants of health:** The circumstances in which people are born, grow, live, work, and age. They are shaped by factors including the individual's income; social status, networks, and environments; employment and working conditions; education and literacy; personal health practices and coping skills; natural biology and genetics; gender and healthy child development; and culture. The allocation of money, power, and resources at global, national, and local system levels are for the most part responsible for individual health and health-service inequities across many countries. Therefore, the aim is to identify and address those factors that lead to disease and injury (Public Health Agency of Canada [PHAC], 2012; WHO, 2013).

**Disease/injury prevention:** “Measures to prevent the occurrence of disease and injury, such as risk factor reduction, but also to arrest the progress and reduce the consequences of disease or injury once established” (Public Health Agency of Canada, 2010). These measures can also include primary-prevention activities that eliminate, control, and reduce the causes or risks or the determinants of poor health in populations and promote factors that are protective of good health (National Public Health Partnership, 2006).

**Education recommendations:** Statements of educational requirements and educational approaches or strategies for the introduction, implementation, and sustainability of the Best Practice Guideline.

**Empowerment:** In this BPG, the term refers to a person having the confidence and knowledge to participate in making informed decisions for their health care. Health-care providers help empower persons to make decisions by discussing evidence-based care and treatment options (according to the person's desired level of involvement and their preferences) that meet the person's health needs and fit their life circumstances.

**Evidence:** Information that comes closest to the facts of a matter. The form it takes depends on context. The findings of high-quality, methodologically appropriate research provides the most accurate evidence. Because research is often incomplete and sometimes contradictory or unavailable, other kinds of information are necessary supplements to, or stand-ins for, research. The evidence base for a decision is the multiple forms of evidence combined to balance rigour with expedience while privileging the former over the latter (Canadian Health Services Research Foundation, 2005).

**Family:** A term used to refer to individuals who are related (biologically, emotionally, or legally) to and/or have close bonds (friendships, commitments, shared households and child rearing responsibilities, and romantic attachments) with the person receiving health care. A person's family includes all those whom the person identifies as significant in his or her life (e.g., parents, caregivers, friends, substitute decision-makers, groups, communities, and populations).

The person receiving care determines the importance and level of involvement of any of these individuals in their care based on his or her capacity (Saskatchewan Ministry of Health, 2011).

**Health:** Health is a state of both illness and wellness, and is not simply the absence of disease. It includes the physical, mental, and social well-being of the person, which fluctuates over the continuum of a person's life (WHO, 1948). Health is viewed as a resource and a process through which individuals, groups, or populations can realize aspirations, satisfy needs, and adapt and cope with changes in the environment (University of Ottawa, 1986).

**Health-care provider:** In this BPG, the term refers to regulated health-care providers or professionals and, in some cases, to unregulated health-care providers who provide care and services to persons and their families in any setting (acute, long-term care, home health care, primary care, and community).

Regulated health-care provider:

In Ontario, the *Regulated Health Professions Act, 1991* (RHPA) provides a framework for regulating 23 health professions, outlining the scope of practice and the profession-specific controlled or authorized acts that each regulated professional is authorized to perform when providing health care and services (CNO, 2014a).

Unregulated health-care provider:

Unregulated health-care providers (UCPs) fulfill a variety of roles in areas that are not subject to the RHPA. They are accountable to their employers but not to an external regulating professional body (e.g., College of Nurses of Ontario). UCPs fulfill a variety of roles and perform tasks that are determined by their employer and employment setting. UCPs only have the authority to perform a controlled act as set out in the RHPA if the procedure falls under one of the exemptions set out in the Act (CNO, 2013c).

**Health literacy:** The knowledge and competences (accessing, understanding, appraising, and applying health information) that a person requires to make decisions and meet the complex demands of their changing states of health (illness and disease) and wellness (prevention). There are two levels of health literacy: the *functional* level, in which the person possesses the basic reading and writing skills required to understand any information given; and the *interactive* level, in which the person possesses more advanced skills that allow them to participate in making decisions regarding their health care, including the ability to critically analyze and make effective use of information to manage health and wellness (National Voices, 2014b; Sorensen et al., 2012).

**Health promotion:** Processes and activities that enable people to have increased control over their health and its determinants. Initiatives for health promotion are directed toward changing the social, environmental, political, and economic conditions that affect public and individual health (National Voices, 2014c; PHAC, 2010).

**Informed consent:** In Ontario, under s. 11 of the *Health Care Consent Act, 1996* (1996), consent for care and treatment is informed if, before providing consent, the person receives information about treatment that a reasonable person under the same circumstances would require to make a decision and receives responses to his/her requests for additional information about the treatment. Information must be provided regarding the nature of treatment; material risks and side effects of the treatment; alternative course of action; and likely consequences of not having the treatment. In addition, consent must relate to the treatment, be informed, be voluntary, and must not be obtained through misrepresentation or fraud. A nurse should not provide treatment if in doubt regarding whether the person understands and is able to consent (CNO, 2013a).

**Interpersonal skills:** Skills (e.g., verbal and non-verbal communication, listening, and leading skills) that enable a person to interact positively and effectively with others in a constructive manner ("Interpersonal skill," 2015).

**Interprofessional health care team:** A team comprised of multiple health-care providers (regulated and unregulated) who work collaboratively to deliver comprehensive and quality health care and services to people within, between, and across health-care settings (Health Care Innovation Working Group, 2012; RNAO, 2013a).

**Macro level:** Micro, meso, and macro is one way of distinguishing between the different levels of the health system (Hoffman et al., 2012). The *macro level* constitutes the domestic or national level of the health system, which is influenced by global (national and international) contexts (Alliance for Health Policy and Systems Research & WHO, 2012).

**Meso level:** Micro, meso, and macro is one way of distinguishing between the different levels of the health system (Hoffman et al., 2012). The *meso level* includes the local or district health system and organizations (Alliance for Health Policy and Systems Research & WHO, 2012).

**Meta-analysis:** A systematic review of randomized controlled trials that uses statistical methods to analyze and summarize the results of the included studies (The Cochrane Collaboration, 2005).

**Micro level:** Micro, meso, and macro is one way of distinguishing between the different levels of the health system (Hoffman et al., 2012). The *micro level* refers to the individuals within the system (e.g., health-care providers, patients, community populace, administrators, and policy-makers) and the interactions between them (Alliance for Health Policy and Systems Research & WHO, 2012).

**Nurse:** Refers to registered nurses, licensed practical nurses (referred to as registered practical nurses in Ontario), registered psychiatric nurses, and nurses in advanced practice roles such as nurse practitioners and clinical nurse specialists (CNO, 2014c; RNAO, 2013a).

**Nursing order set:** A nursing order set is a group of evidence-based interventions specific to the domain of nursing. Nursing order sets are ordered independently by nurses (i.e., without a physician's signature) to standardize the care provided for a specific clinical condition or situation (in this case, person- and family-centred care).

**Person-centred-care attitudes and behaviours:** *Person-centred-care attitudes* reflect the health-care provider’s belief in the importance of coming to know the whole person (biopsychosocial and spiritual) when assessing the person’s condition. They also include a belief in the person’s ability to make a decision; the health-care provider therefore promotes autonomy and the sharing of power.

*Person-centred-care behaviours* are the observed characteristics of health-care providers corresponding to person-centred-care attitudes, including verbal behaviours (e.g., asking questions in a way that shows respect, caring, and interest in what the person is saying) and non-verbal behaviours (e.g., sitting down and facing the person when speaking to them so the person feels like they are in a collegial partnership). Attitudes and behaviours are both important components of patient-centred care (Duggan et al., 2006).

**Person:** In this BPG, the term refers to any individual(s) with whom health-care providers establish a therapeutic relationship for the purposes of partnering for health. The term *person* is inclusive of the following: individual, client, patient, resident, consumer, *and their family* (parent and others such as significant others, caregivers, friends, substitute decision-makers, groups, communities, and populations) (CNO, 2013b, 2013c; Mental Health Commission of Canada, 2009).



**Person- and family-centred care:** A person- and family-centred approach to care demonstrates certain practices that put the person and their family members at the centre of health care and services. Person- and family-centred care respects and empowers individuals to be genuine partners with health-care providers for their health. The approach includes the following common themes and attributes:

- Fostering relationships and trust;
- Empowering the person to be actively involved in making decisions regarding their health care (independence and autonomy, right to self-determination);
- Sharing of evidence-based options for care, education, and information that is unbiased, clear, and comprehensive to support the person in making decisions;
- Respecting the person and personalizing care by promoting the person's strengths, self-knowledge, preferences, and goals for care based on their beliefs, values, culture, and their experience of health;
- Providing physical comfort within an environment that is conducive to healing;
- Offering emotional support and sympathetic presence;
- Ensuring continuity of care during transitions;
- Ensuring the person's ability to access care and services when needed;
- Partnering with the person and their family in health system reform to improve the quality, delivery, and design of health care and services at all levels (micro, meso, and macro);
- Communicating effectively within a therapeutic relationship to promote true health-care partnerships; and
- Caring for individuals, their families, and communities by addressing determinants of health (health promotion and disease prevention)

(Balik, Conway, Zipperer, & Watson, 2011; CNO, 2013a, 2013b; College of Registered Nurses of Manitoba, 2013; McCormack et al., 2010; RNAO, 2002, 2006a, 2006b, 2010, 2014a; Saskatchewan Ministry of Health, 2011).

There are several terms and definitions representing variations on the concept of person- and family-centred care and its dimensions that contain similar fundamental components. These are as follows:

**Client-centred care:** An approach in which clients are viewed as whole; it is not merely about delivering services where the client is located. Client-centred care involves advocacy, empowerment, and respecting the client's autonomy, voice, self-determination, and participation in decision making (RNAO, 2002, 2006a).

**Family-centred care:** An approach to care in which the family – rather than just the identified patient – is viewed as the unit of care; they are respected and viewed part of an integral whole (RNAO, 2002, 2006a).

**Patient- and family-centred care:** An approach to care that recognizes the importance of family and in a patient's life and the importance of their active involvement in planning and making decisions on health care, services and treatment, and health system reform. This approach to care provides respectful, compassionate, culturally safe, and responsive care that meets the needs, values, beliefs, and preferences of the patient, their family, and others identified as significant to their life from diverse backgrounds and settings (Saskatchewan Ministry of Health, 2011).

**Person-centred care:** An approach to care in which the person is viewed as whole. The process of coming to know the whole person is nurtured through the formation of a therapeutic relationship between the person, those who are significant to them, and health-care providers. This approach to care involves advocacy, empowerment, and mutual respect and understanding of the person's right to be autonomous, to self-determine, and to actively participate in decisions about their health (illness and wellness) (CNO 2013b; McCormack et al., 2010; RNAO, 2002, 2006a).

**Person and family’s experience:** This term refers to how the person and their family think and feel about what happens when they use the health system and services. Aspects of care that contribute to this experience include: access to reliable advice; effective treatment; involvement in decisions with respect given to their preferences; clear, comprehensive information to support self-care; attention to physical and environmental needs; emotional support (sympathetic presence and respect, and support of family/caregivers); and continuity of care to ensure smooth transitions (National Voices, 2014a).

**Practice recommendations:** Statements of best practice directed at health-care providers which enable the successful implementation of the Best Practice Guideline; ideally, they are based on evidence.

**Primary care medical home model:** This model for primary care delivery requires a strong primary care workforce of multidisciplinary health-care providers working as a team to meet the majority of needs of their patients. The five domains associated with this model are: 1) comprehensive care; 2) patient-centred care; 3) coordinated care across providers, settings, and transitions; 4) timely access to care; and 5) the delivery of safe and high-quality care (Agency for Healthcare Research and Quality, 2014a).

**Qualitative research:** Research that uses an interactive and subjective approach to investigate and describe phenomena (e.g., lived experience) and to give them meaning. The nature of this type of research is exploratory and open-ended. Analysis involves the organization and interpretation of non-numerical data (e.g., Phenomenology, Ethnography, Grounded Theory, Case Study, etc.) (Speziale & Carpenter, 2007).

**Quality:** The degree to which health-care services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge (The World Alliance for Patient Safety Drafting Group, 2009).

**Quasi-experimental study:** A study that lacks randomization and a control group and therefore is not considered a “true” experimental design (e.g., a randomized controlled trial). The investigator controls the assignment to the intervention, exposure, or treatment by using some criterion other than random assignment (e.g., pre-post design) (Polit, Beck, & Hungler, 2001).

**Randomized controlled trial (RCT):** An experiment in which the investigator assigns an intervention, exposure, or treatment to participants who are randomly allocated to either the experimental group (receives intervention) and the comparison (conventional treatment) or control group (no intervention or placebo) (The Cochrane Collaboration, 2005). The participants are followed and assessed to determine the efficacy of the intervention. Includes double-blind, single-blind and non-blind trials.

**Reflective practice:** Reflective practice (sometimes referred to as *self-awareness*) is an important component of a therapeutic relationship and can be defined as the ability to reflect on one’s practice, thoughts, feelings, needs, fears, strengths, and weaknesses, and to understand how these might affect one’s actions and the nurse–client relationship (RNAO, 2006b).

**Self-management:** Self-management refers to all of the actions taken by individuals to live well – that is, the ability and confidence to recognize, treat, and manage (medically and emotionally) their health and wellness either independently or in partnership with other health-care providers (National Voices, 2014d; RNAO, 2010).

**Shared decision making:** This approach to making decisions is based on an acknowledgment of each person's individual autonomy and right to self-determination (i.e., the freedom to make one's own decisions and control one's life). It relies on information from two experts: the health-care provider (the expert on evidence-based practices) and the person making the decisions for their health. The person is the expert on themselves (i.e., their beliefs, culture, spirituality and values), their experience of health, and their life circumstances (social world and lived experiences with health). Together, these experts share and discuss the best options for health care and services so the person can make a decision and choose the best option for them.

Health-care providers support the person in the decision-making process by ensuring the following:

1. The options for care based on best evidence are shared;
2. Information is given on each option and discussed in detail with the person as they consider each option to make an informed choice (based on benefits, risks, and costs);
3. The person explores their preferred options based on their values, beliefs, culture, and life circumstances;
4. The person's belief and ability to self-manage their care is reviewed and discussed with health-care providers;
5. The person's understanding is checked and clarified;
6. The person makes an explicit decision or defers their final decision; and
7. There is follow-up based on the person's decision

(Elwyn et al., 2012; Légaré et al., 2010; National Voices, 2014e).

*See decision-making process*

**Stakeholder:** An individual, group, or organization that has a vested interest in the decisions and actions of organizations and may attempt to influence decisions and actions (Baker et al., 1999). Stakeholders include all individuals and groups who will be directly or indirectly affected by the change or solution to the problem.

**Substitute decision-maker:** A person identified by the *Health Care Consent Act, 1996* (1996) as having the capacity to make treatment decisions for someone who is deemed not capable (CNO, 2013a).

**Sympathetic presence:** Unlike empathy (knowing and understanding), sympathetic presence is about being affected by another person's feelings. Sympathetic presence is a way for health-care providers to convey acceptance of the person as a unique individual and their feelings. Health-care providers can demonstrate sympathetic presence by being with and listening to the person, and by using sensitive, supportive, and caring behaviours to reflect that they are affected by the person's losses and limitations. Sympathetic presence is dependent on having insight into the whole person and assisting them to maximize their ability cope with their experience of health (McCormack & McCance, 2010).

**System, organization and policy recommendations:** Statements of conditions required for a practice setting that enable the successful implementation of the Best Practice Guideline. The conditions for success are largely the responsibility of the organization, although they may have implications for policy at a broader governmental or societal level.

**Systematic review:** A review that “attempts to collate all empirical evidence that fits pre-specified eligibility criteria in order to answer a specific research question” (The Cochrane Collaboration, 2011). A systematic review uses systematic, explicit, and reproducible methods to identify, select, and critically appraise relevant research, and to collect and analyze data from the studies that are included in the review (The Cochrane Collaboration, 2005, 2011).

**Teach back:** This is a core communication technique used by health-care providers when sharing information for self-management of care. The technique is known as closing the loop whereby health-care providers ensure the person understands the information he/she has received. The person is asked to repeat back in their own words the shared information. The health-care provider then assesses the person’s understanding and clarifies any misunderstanding of the information (RNAO, 2010).

**Therapeutic relationship:** A purposeful, goal-directed relationship between the health-care provider and the person accessing the health system for care and treatment that is grounded in an interpersonal process directed at advancing the best interest and outcome of the person (CNO, 2013b; RNAO, 2006b).

**Whole person:** All of the components – biological, psychological, emotional, physical, personal, social, environmental, and spiritual – that make up a person. Caring for the whole person entails coming to know the person with respect to all of these components and treating the person holistically rather than treating only their illness or disease (Lovering, 2012; Morgan & Yoder, 2012).





## Appendix B: Guideline Development Process

The Registered Nurses' Association of Ontario (RNAO) has made a commitment to ensure that every BPG is based on the best available evidence. To meet this commitment, a monitoring and revision process has been established for each Guideline every five years.

For this revised Guideline, RNAO assembled a panel of experts who represent a range of sectors and practice areas (see the RNAO Expert Panel section at the beginning of this Guideline). A systematic review of the evidence was based on the purpose and scope of the original Guideline, *Client Centred Care* (RNAO, 2002), and the revision supplement (RNAO, 2006a), and was supported by five clinical questions. The systematic review captured relevant literature and guidelines published between June 2005 and April 2014. The following research questions were established to guide the systematic review:

1. What is person-centred care?
  - a) How is person-centred care defined?
  - b) What are the components of person-centred care?
2. What nursing or health-care provider behaviours demonstrate a person-centred approach during the delivery (assessment, planning, management, and evaluation) of care to a person?
3. What are the evidence-based models of care delivery that demonstrate effective outcomes and support person-centred care?
  - a) Components of effective person-centred care models?
  - b) Enablers to the provision of the person-centred care in the model?
  - c) Barriers to the provision of person-centred care in the model?
  - d) Impact on satisfaction with care within all health settings?
4. What components of person-centred care should be taught in basic curricula or ongoing professional education programs?
5. What organizational or system structures support successful implementation of person-centred care?

The expert panel's mandate was to review the original Guideline and the revision supplement in light of the new evidence to ensure the continuing validity, appropriateness, and safety of the recommendations. This new revised Guideline is the result of the expert panel's work to integrate the most current and best evidence into the recommendations with the supporting evidence from original Guideline and the revision supplement (where applicable).

# Appendix C: Process for Systematic Review and Search Strategy

## Guideline Review

The Registered Nurses' Association of Ontario (RNAO) guideline development team's project coordinator searched an established list of websites for guidelines and other relevant content published between June 2005 and April 2014. This list was compiled based on knowledge of evidence-based practice websites, recommendations from the literature, and key websites related to person- and family-centred-care practices. Furthermore, expert panel members were asked to provide guidelines from their own personal libraries. Detailed information about the search strategy for existing guidelines, including the list of websites searched and inclusion criteria, is available online at [www.RNAO.ca](http://www.RNAO.ca).

Members of the expert panel critically appraised five international guidelines using the *Appraisal of Guidelines for Research and Evaluation Instrument II* (Brouwers et al. 2010). From this review, the following four guidelines were selected to inform the recommendations and discussions of evidence:

Alzheimer Society. (2011). *Guidelines for care: Person-centred care of people with dementia living in care homes*. Retrieved from [http://www.alzheimer.ca/~media/Files/national/Culture-change/culture\\_change\\_framework\\_e.pdf](http://www.alzheimer.ca/~media/Files/national/Culture-change/culture_change_framework_e.pdf)

Health Education and Training Institute. (2012). *Best practice governance framework for allied health education and training: Guidelines to support the development of allied health capabilities in the delivery of person-centred care*. Retrieved from <http://www.heti.nsw.gov.au/resources-library/allied-health-best-practice-governance-framework/>

National Institute for Health and Clinical Excellence. (2012). *Patient experience in adult NHS services: Improving the experience of care for people using adult NHS services*. Retrieved from <http://www.nice.org.uk/guidance/CG138>

✚ Evidence update: National Institute for Health and Clinical Excellence. (2014). *Patient experience in adult NHS services: Evidence update 52*. Retrieved from <https://www.evidence.nhs.uk/>

Richmond PRA. (2013). *Good practice guidelines for person-centred planning and goal setting for people with psychosocial disability. A project report for Disability Care Australia*. Retrieved from [http://www.ndis.gov.au/sites/default/files/documents/Project\\_Report\\_Final.pdf](http://www.ndis.gov.au/sites/default/files/documents/Project_Report_Final.pdf)

## Systematic Review

A comprehensive search strategy was developed by RNAO's research team and a health sciences librarian, based on inclusion and exclusion criteria created with the RNAO expert panel. A search for relevant articles in English published between June 2005 and April 2014 was applied to the following databases: Cumulative Index to Nursing and Allied Health (CINAHL), Cochrane Central Register of Controlled Trials (CENTRAL), Cochrane Database of Systematic Reviews (CDSR), Database of Abstracts of Reviews of Effects (DARE), Education Resources Information Center (ERIC), Embase, Joanna Briggs Institute, MEDLINE, MEDLINE in Progress, and PsycINFO. In addition to this systematic search, panel members were asked to review personal libraries for key articles not found through the above search strategies.

Detailed information about the search strategy for the systematic review, including the inclusion and exclusion criteria as well as search terms, is available at [www.RNAO.ca/bpg/person-care](http://www.RNAO.ca/bpg/person-care)

Once articles were retrieved, two RNAO BPG nursing research associates (nurses holding master's degrees) independently assessed the eligibility of the studies according to established inclusion/exclusion criteria. The RNAO's BPG program manager, involved in supporting the RNAO expert panel, resolved disagreements.

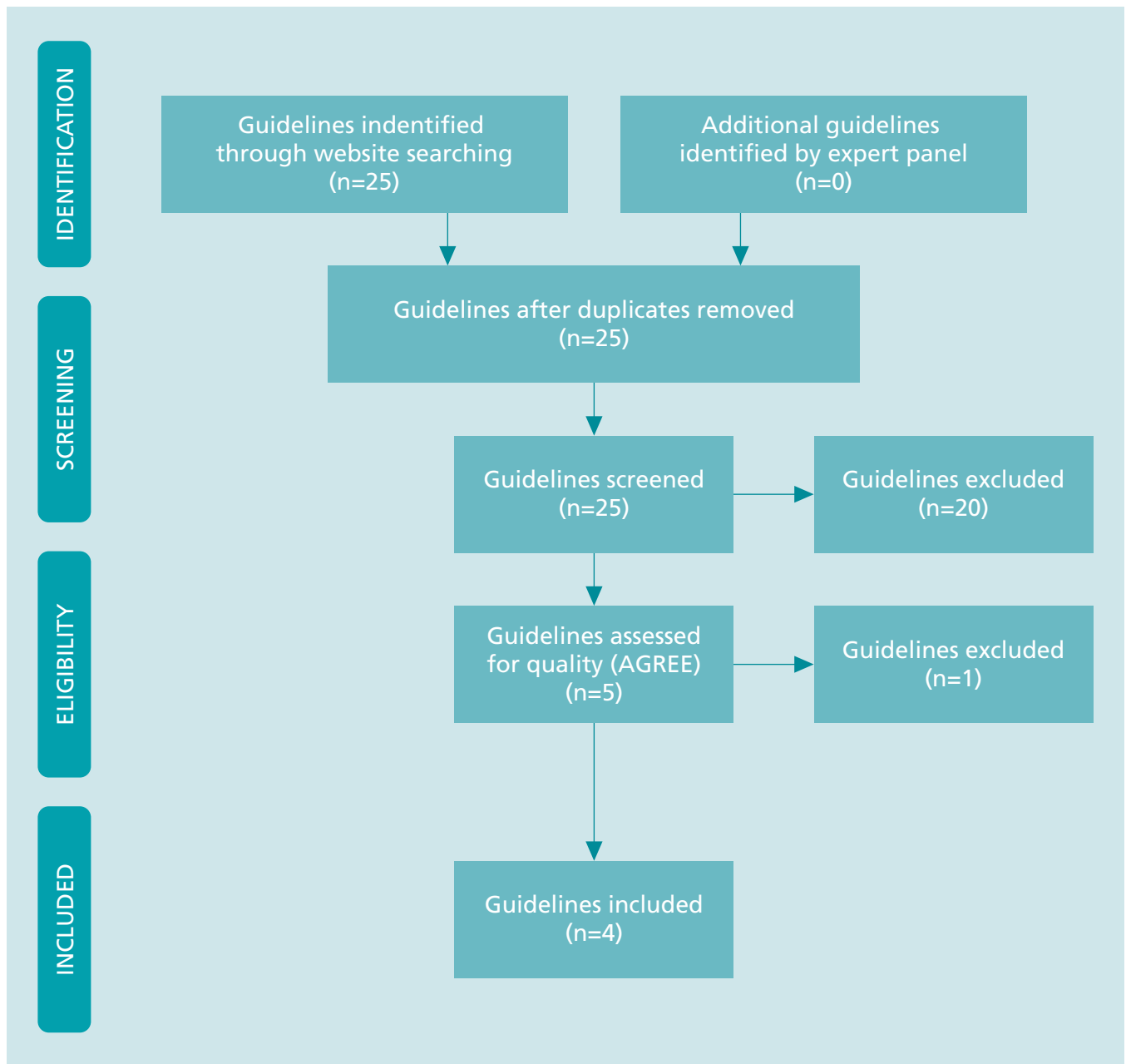
Quality appraisal scores for 9 articles (a random sample of 20% of articles eligible for data extraction and quality appraisal) were independently assessed by RNAO BPG research associates. Acceptable inter-rater agreement (kappa statistic,  $K=0.83$ ) justified proceeding with quality appraisal and data extraction by dividing the remaining studies equally between the two research associates (Fleiss, Levin, & Paik, 2003). A final summary of literature findings was completed. The comprehensive data tables and summary were provided to all expert panel members for review and discussion.

A review of the most recent literature and relevant guidelines published between June 2005 and April 2014 resulted in an update of the existing recommendations as well as the inclusion of new recommendations.

A complete Bibliography of all full text articles screened for inclusion is available at: [www.RNAO.ca/bpg/person-care](http://www.RNAO.ca/bpg/person-care)

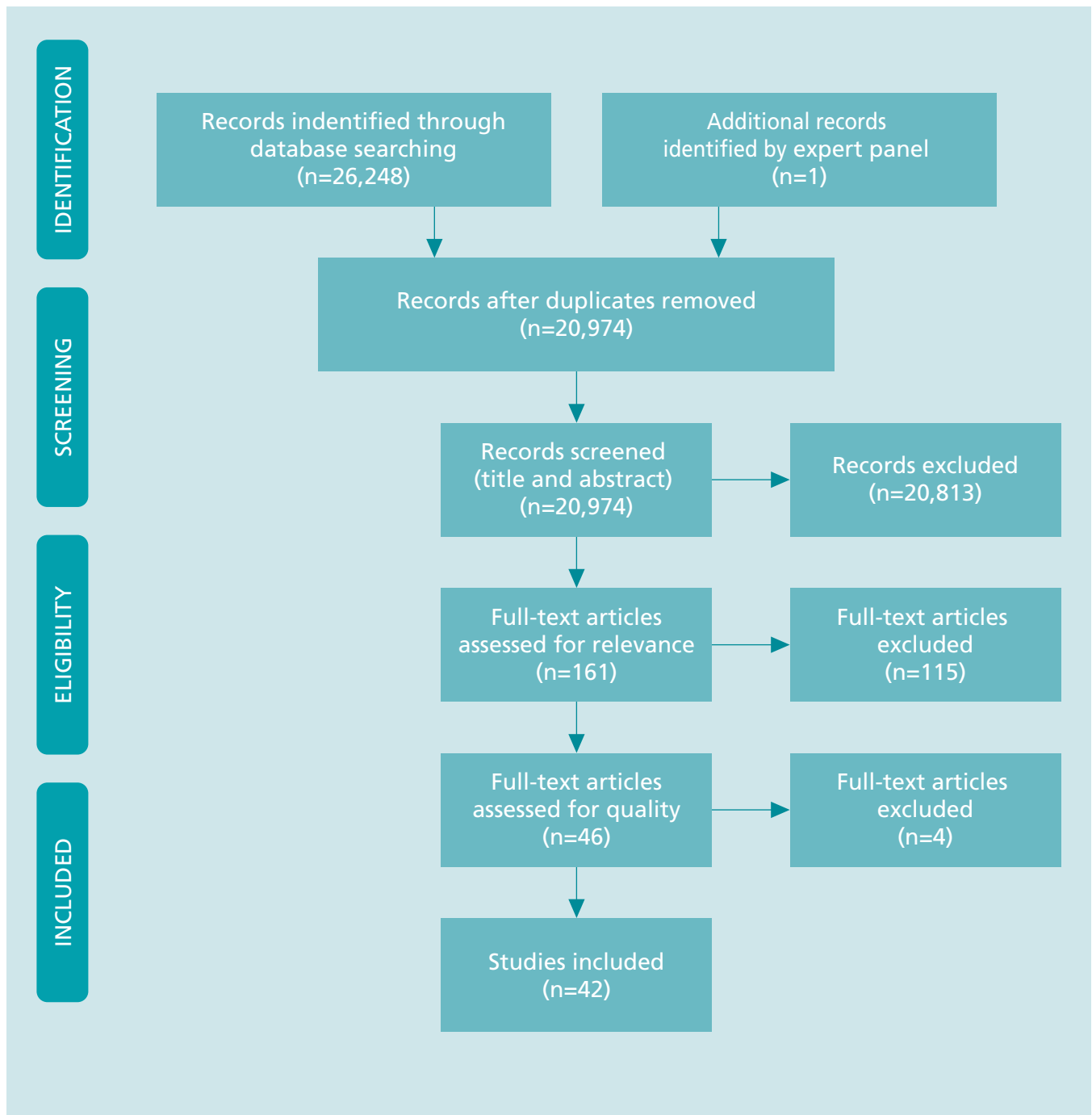


### Guideline Review Process Flow Diagram



Flow diagram adapted from D. Moher, A. Liberati, J. Tetzlaff, D. G. Altman, and The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analysis: The PRISMA Statement. *BMJ*, 339, b2535, doi: 10.1136/bmj.b2535

Article Review Process Flow Diagram



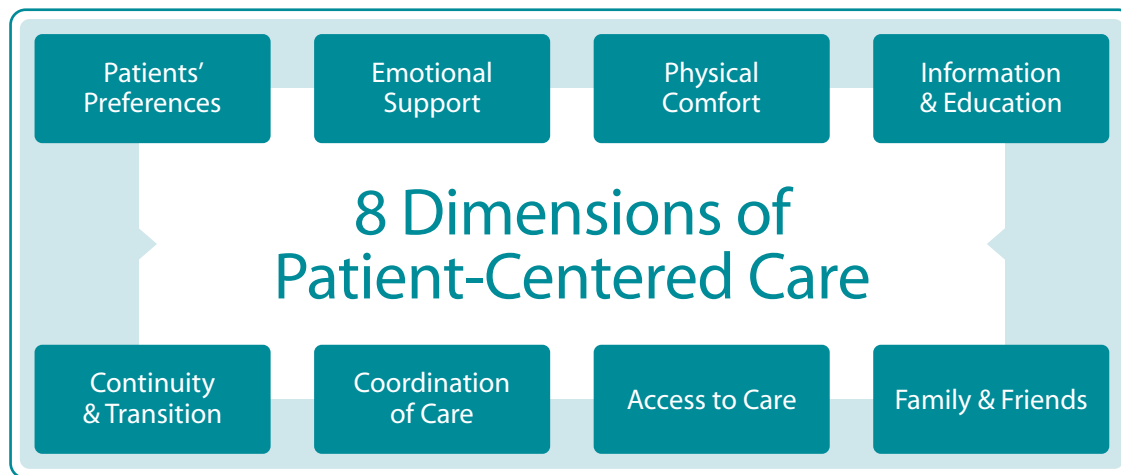
APPENDICES

Flow diagram adapted from D. Moher, A. Liberati, J. Tetzlaff, D. G. Altman, and The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analysis: The PRISMA Statement. *BMJ*, 339, b2535, doi: 10.1136/bmj.b2535

# Appendix D: Eight Dimensions of Patient-Centered Care

The following eight dimensions of patient-centred care, also known as the Eight Picker Principles of Patient-Centered Care, were identified through research by the Picker Institute and Harvard Medical School. The research involved gathering information from diverse focus groups – including patients, physicians and other hospital staff, and family members – regarding their health-care experiences, and reviewing relevant literature to determine what matters most to patients. Figure 2 illustrates the eight dimensions of patient-centred care. The discussion of the eight principles below is adapted from the Picker Institute (1987).

**Figure 2. Eight Dimensions of Patient-Centered Care**



Source: Reprinted from *Eight Dimensions of Patient-Centered Care*, by National Research Corporation Canada. Retrieved from <http://www.nationalresearch.com/products-and-solutions/patient-and-family-experience/eight-dimensions-of-patient-centered-care>. Copyright 2015 by National Research Corporation Canada. Reprinted with permission.

## Eight Principles of Patient-Centered Care

### 1. *Respect for Patients' Values, Preferences, and Expressed Needs*

- Treating individuals with respect, in a way that maintains their dignity and demonstrates sensitivity to their cultural values
- Keeping individuals informed about their condition and involving them in decision making
- Focusing on the person's quality of life, which may be affected by their illness and treatment

## 2. *Coordination and Integration of Care*

- Coordinating and integrating clinical and patient care and services to reduce feelings of fear and vulnerability

## 3. *Information and Education*

- Providing complete information to individuals regarding their clinical status, progress, and prognosis; process of care; and information to help ensure their autonomy and their ability to self-manage, and to promote their health

## 4. *Physical Comfort*

- Enhancing individuals' physical comfort during care, especially with regard to pain management, support with the activities of daily living, and maintaining a focus on the hospital environment (e.g., privacy, cleanliness, comforts, accessibility for visits)

## 5. *Emotional Support and Alleviation of Fear and Anxiety*

- Helping to alleviate fear and anxiety the person may be experiencing with respect to their health statute (physical status, treatment, and prognosis), the impact of their illness on themselves and others (family, caregivers, etc.), and the financial impacts of their illness

## 6. *Involvement of Family and Friends*

- Acknowledging and respecting the role of the person's family and friends in their health-care experience by:
  - Accommodating the individuals who provide the person with support during care
  - Respecting the role of the person's advocate in decision making
  - Supporting family members and friends as caregivers, and recognizing their needs

## 7. *Continuity and Transition*

- Alleviating anxiety about the person's ability to self-manage after discharge by:
  - Providing information regarding medication, physical restrictions, nutrition, etc.;
  - Coordinating ongoing treatment and services and sharing this information with the person and their family; and
  - Providing information regarding access to supports (e.g., social, physical, and financial) on an ongoing basis

## 8. *Access to Care*

- Ensuring, mainly with respect to ambulatory care:
  - Access to multiple health-care settings and services
  - Availability of transportation
  - Ease of scheduling and availability of appointments
  - Access to specialists and specialty services when needed

Reference: Picker Institute. (1987). *Principles of patient-centered care*. Retrieved from <http://pickerinstitute.org/about/picker-principles/>

## Appendix E: Additional Resources

The expert panel, with input from external stakeholder reviewers, has compiled a list of some of the main organizations that provide information and resources on person- and family-centred care.

Links to websites that are external to the RNAO website are provided for information purposes only. RNAO is not responsible for the quality, accuracy, reliability, or currency of the information provided through these sources. Further, RNAO has not determined the extent to which these resources have been evaluated. Questions related to these resources should be directed to the source.

WEBSITE NAME	CONTENTS	LINK
Agency for Healthcare Research & Quality (AHRQ)	Guide to Patient and Family Engagement in Hospital Quality and Safety	<a href="http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/index.html">http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/index.html</a>
	Strategies for Leadership – Patient- and Family-Centered Care Hospital Self-Assessment Inventory. This document contains links to resources on the following topics: <ul style="list-style-type: none"> <li>■ Assessing patient- and family-centered care practices at your hospital</li> <li>■ General resources</li> <li>■ Getting started with patient- and family-centered care and patient and family engagement</li> <li>■ Improving discharge practices</li> <li>■ Improving informed consent practices</li> <li>■ Medication reconciliation</li> <li>■ Other resources for improving patient- and family-centered care practices</li> <li>■ Patient- and family-activated rapid response teams</li> <li>■ Patient safety</li> <li>■ Quality improvement</li> <li>■ Working with patients and families as advisors</li> </ul>	<a href="http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/howtogetstarted/Ways_To_Learn_More_508.pdf">http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/howtogetstarted/Ways To Learn More 508.pdf</a>



WEBSITE NAME	CONTENTS	LINK
Agency for Healthcare Research & Quality (AHRQ)	Patient Centered Medical Home Resource Center: <ul style="list-style-type: none"> <li>■ Defining the PCMH</li> <li>■ Evidence and Evaluation</li> <li>■ Implementing the PCMH                             <ul style="list-style-type: none"> <li>● PCPF Resources</li> <li>● PCPF Webinars</li> <li>● Practice Facilitation</li> </ul> </li> <li>■ Federal PCMH Activities</li> <li>■ Tools and Resources                             <ul style="list-style-type: none"> <li>● Accessible Services</li> <li>● Comprehensive Care</li> <li>● Coordinated Care</li> <li>● Foundations</li> <li>● Patient-Centered</li> <li>● Quality and Safety</li> </ul> </li> <li>■ Citations Collection</li> </ul>	<a href="http://www.pcmh.ahrq.gov/page/patient-centered-care">http://www.pcmh.ahrq.gov/page/patient-centered-care</a>  <a href="http://pcmh.ahrq.gov/citations-patient-centered-care?items_per_page=All">http://pcmh.ahrq.gov/citations-patient-centered-care?items_per_page=All</a>  <a href="http://pcmh.ahrq.gov/citations-patient-centered-care?items_per_page=All">http://pcmh.ahrq.gov/citations-patient-centered-care?items_per_page=All</a>
Alberta Human Services	Additional and background resources about Person Centered Planning in Central Alberta: <ul style="list-style-type: none"> <li>■ Individual and Family Stories</li> <li>■ PCP Fact Sheet</li> <li>■ PCP Literature Review</li> <li>■ PCP Pilot Site Contacts</li> <li>■ PCP Pilot Site Evaluations</li> <li>■ PCP Q &amp; A</li> <li>■ PCP Research Project Results – June 2005</li> <li>■ PCP Resources and Links</li> <li>■ Person Centered Planning Guidebook</li> <li>■ Person Centered Planning Tools</li> <li>■ Why it Matters Booklet</li> </ul>	<a href="http://humanservices.alberta.ca/disability-services/pdd-central-publications-person-centered-planning.html">http://humanservices.alberta.ca/disability-services/pdd-central-publications-person-centered-planning.html</a>

WEBSITE NAME	CONTENTS	LINK
Algoma Public Health	Algoma Client-Centred Care Tool: An Evaluation Scale for Assessing Staff Use of Client-Centred Practices	<a href="http://www.puckett.org/Practical%20Evaluation%20reports/CPE_Report_Vol-5No2.pdf">http://www.puckett.org/Practical%20Evaluation%20reports/CPE_Report_Vol-5No2.pdf</a>
American Hospital Association	<ul style="list-style-type: none"> <li>■ Hospital Self-Assessment Tool</li> <li>■ Resource Guide</li> <li>■ Video: Patient- and Family-Centered Care</li> </ul>	<a href="http://www.aha.org/advocacy-issues/quality/strategies-patient-centered.shtml">http://www.aha.org/advocacy-issues/quality/strategies-patient-centered.shtml</a>
American Institutes for Research	Roadmap Guides Patient and Family Engagement in Healthcare	<a href="http://www.air.org/project/roadmap-guides-patient-and-family-engagement-healthcare">http://www.air.org/project/roadmap-guides-patient-and-family-engagement-healthcare</a>
Canadian Foundation for Healthcare Improvement	Patient and Family Engagement	<a href="http://www.cfhi-fcass.ca/WhatWeDo/PatientEngagement.aspx">http://www.cfhi-fcass.ca/WhatWeDo/PatientEngagement.aspx</a>
Canadian Patient Safety Institute	Patients for Patient Safety Canada <ul style="list-style-type: none"> <li>■ Resources (videos, documents, stories)</li> </ul>	<a href="http://www.patientsforpatient-safety.ca/English/Pages/default.aspx">http://www.patientsforpatient-safety.ca/English/Pages/default.aspx</a>
Centre for Health Information and Decision Systems (University of Maryland)	Emerging Technologies for Patient Engagement and Mobile Health (Presentations): <ul style="list-style-type: none"> <li>■ Member and Family Engagement: Digital Workforce Group</li> <li>■ Patient engagement-with-mobile-apps-the-diy-guide</li> <li>■ Forms of community participation among older people luana valletta</li> <li>■ Mobile Health for Multiple Sclerosis</li> <li>■ Towards Hybrid Informal Learning Spaces: Designing for Digital Encounters in Physical Environments</li> <li>■ Dealing With Patients Who Surf the Net</li> <li>■ 8 New Technologies Revolutionizing Health and Fitness</li> <li>■ Patient Engagement and Patient Empowerment</li> </ul>	<a href="http://www.slideshare.net/kenyon-crowley/crowley-do-dva-ehr-symposium-oct-1-2013-final">http://www.slideshare.net/kenyon-crowley/crowley-do-dva-ehr-symposium-oct-1-2013-final</a>

WEBSITE NAME	CONTENTS	LINK
Cleveland Clinic: Patient Experience Advisory Group	Communicate with H.E.A.R.T. Education Program to Support Improvement in Communication with Patient, Family and Coworkers	<a href="http://www.patient-experienceadvisorygroup.org/education/service-excellence-training/communicate-with-h-e-a-r-t/">http://www.patient-experienceadvisorygroup.org/education/service-excellence-training/communicate-with-h-e-a-r-t/</a>
Guidelines International Network (GIN)	G-I-N PUBLIC Toolkit: Patient and Public Involvement in Guidelines	<a href="http://www.g-i-n.net/working-groups/gin-public/toolkit">http://www.g-i-n.net/working-groups/gin-public/toolkit</a>
IDA Institute (Hearing Co-operation)	<ul style="list-style-type: none"> <li>■ <i>Clinical Tools for Appointments</i>: Patient Motivation Assessment, Involving Communication Partners, Living Well with Hearing Loss (Daily QOL &amp; special needs), My World Pediatric Tool (Child’s perspective).</li> <li>■ <i>Professional Skills Development &amp; Reflection Tools</i>: Time and Talk, Change Guide – Patient Change Journey, E-Learning Lab, Self-Development in the Clinic, Video Library.</li> <li>■ Tool room with tools to help open communication and engage patients in self management of their hearing loss by better understanding their needs and wishes and incorporating them into their rehabilitation plan of care.</li> <li>■ <i>Tools for Academics and Educators</i>: Clinical Supervisor Kit</li> </ul>	<a href="http://idainstitute.com/">http://idainstitute.com/</a>
Institute for Healthcare Improvement (IHI)	Person- and Family-Centred Care Tools and Resources: <ul style="list-style-type: none"> <li>■ Achieving an Exceptional Patient and Family Experience of Inpatient Hospital Care</li> <li>■ Partnering with Patients and Families: A Roadmap for the Future</li> <li>■ Partnering with Patients and Families: Recommendations and Promising Practices</li> <li>■ Patient- and Family-Centered Care Organizational Self-Assessment Tool</li> </ul>	<a href="http://www.ihl.org/Pages/default.aspx">http://www.ihl.org/Pages/default.aspx</a>

WEBSITE NAME	CONTENTS	LINK
Institute for Patient- and Family-Centred Care	Special Topics: <ul style="list-style-type: none"> <li>■ Better Together: Partnering with Families</li> <li>■ Environment and Design</li> <li>■ Geriatric Care</li> <li>■ Medical Education</li> <li>■ Parental Illness</li> <li>■ Patient and Family Advisory Council</li> <li>■ Patient and Family Resource Center</li> <li>■ Picker Institute</li> <li>■ Primary Care/Medical Home</li> <li>■ Videos</li> <li>■ Visiting Family Presence</li> </ul>	<a href="http://www.ipfcc.org/">http://www.ipfcc.org/</a>
National Health Services England	Patient- and Family-Centred Care: <ul style="list-style-type: none"> <li>■ Patient Involvement</li> <li>■ Putting Patients First</li> </ul>	<a href="http://www.england.nhs.uk/">http://www.england.nhs.uk/</a>
	Making Patient-Centred Care Real: The Road to Implementation	<a href="http://www.change-foundation.ca/library/making-patient-centred-care-real-the-road-to-implementation/">http://www.change-foundation.ca/library/making-patient-centred-care-real-the-road-to-implementation/</a>
National Quality Forum	<ul style="list-style-type: none"> <li>■ Measures of Person- and Family-Centred Care</li> </ul>	<a href="http://www.quality-forum.org/Topics/Patient%20and%20Family%20Engagement.aspx">http://www.quality-forum.org/Topics/Patient and Family Engagement.aspx</a>

WEBSITE NAME	CONTENTS	LINK
NICE Guidelines	<ul style="list-style-type: none"> <li>■ NICE Pathways on Patient Experience in Adult NHS Service</li> </ul>	<a href="http://pathways.nice.org.uk/">http://pathways.nice.org.uk/</a>
	<ul style="list-style-type: none"> <li>■ Assessment Tools &amp; Checklists</li> <li>■ Community and Consumer Engagement Resources &amp; Toolkits</li> <li>■ National and International Resources on Organization Design and Getting Engagement/Involvement (Alberta, British Columbia, Saskatchewan, Cancer Care Ontario, Scotland, Australia, King Fund; NHS England)</li> <li>■ Recruitment of Patient and Families in Advisory Roles</li> <li>■ Using Online Tools to Engage the Public Report</li> </ul>	<a href="http://www.cfhi-fcass.ca/WhatWeDo/PatientEngagement/PatientEngagementResourceHub.aspx">http://www.cfhi-fcass.ca/WhatWeDo/PatientEngagement/PatientEngagementResourceHub.aspx</a>
Ottawa Hospital Research Institute	Patient Decision Aides	<a href="http://decisionaid.ohri.ca/">http://decisionaid.ohri.ca/</a>
Partnerships in Dementia Care Alliance	Culture Change Living Toolkit: <ul style="list-style-type: none"> <li>■ Reflective of person-centred and relational care in dementia and long-term care</li> </ul>	<a href="https://uwaterloo.ca/partnerships-in-dementia-care/culture-change-living-toolkit/">https://uwaterloo.ca/partnerships-in-dementia-care/culture-change-living-toolkit/</a>

WEBSITE NAME	CONTENTS	LINK
Picker Institute	Principles of Patient-Centred Care	<a href="http://pickerinstitute.org/about/picker-principles/">http://pickerinstitute.org/about/picker-principles/</a>
	Patient- Centred Care Improvement Guide <ul style="list-style-type: none"> <li>■ Access to Information and Patient Education</li> <li>■ Care for the Caregiver</li> <li>■ Caring for the Community</li> <li>■ Communicating Effectively With Patients And Families</li> <li>■ Continuity of Care</li> <li>■ Environment of Care</li> <li>■ Family Involvement</li> <li>■ How To Use The Patient-Centered Care Guide</li> <li>■ Integrative Medicine</li> <li>■ Patient-Centered Approaches To Data And Technology</li> <li>■ Patient-Centered Care And HCAHPS</li> <li>■ Patient-Centered Care As Culture Change</li> <li>■ Patient-Centered Care Leadership Roundtable Participants</li> <li>■ Patient-Centered Care: A Idea Whose Time Has Come</li> <li>■ Personal Strategies: What You Can Do Now</li> <li>■ Personalization of Care</li> <li>■ Practical Approaches For Building A Patient-Centered Culture</li> <li>■ Setting The Stage</li> <li>■ Spirituality</li> <li>■ The Myths of Patient-Centered Care</li> <li>■ List of Practices at a Glance</li> </ul>	<a href="http://pickerinstitute.org/">http://pickerinstitute.org/</a> <a href="http://www.patient-centeredcare.org/inside/aboutthe-guide.html">http://www.patient-centeredcare.org/inside/aboutthe-guide.html</a>
Planetree and The Harvey Picker Centre	Long Term Care Improvement Guide	<a href="http://www.residentcenteredcare.org/">http://www.residentcenteredcare.org/</a>

WEBSITE NAME	CONTENTS	LINK
Royal College of Nursing	Resources and tools: <ul style="list-style-type: none"> <li>■ Standards</li> <li>■ Stories and good practice examples</li> </ul>	<a href="http://www.rcn.org.uk/development/practice/dementia/supporting_people_with_dementia/person-centred_care_planning">http://www.rcn.org.uk/development/practice/dementia/supporting_people_with_dementia/person-centred_care_planning</a>
Saint Elizabeth Health Care	Resources available on person-centered: <ul style="list-style-type: none"> <li>■ Comprehensive literature review of person-centred care in the home and community sector</li> <li>■ Facts sheets that provide a quick reference to key information from the literature review</li> <li>■ Online, searchable inventory of resources, programs and publications related to person-centred care in the home and community health care sector</li> <li>■ Practical guide to implementing person-centred care education for Personal Service Workers in the home, community and long-term care sector</li> <li>■ Promising practices case studies</li> </ul>	<a href="http://www.saintelizabeth.com/Services-and-Programs/Research/Client-Centered-Care.aspx">http://www.saintelizabeth.com/Services-and-Programs/Research/Client-Centered-Care.aspx</a>
The Beryl Institute	<ul style="list-style-type: none"> <li>■ Publications on key issues impacting the patient experience</li> <li>■ Case studies identifying practices known to improve the patient experience</li> <li>■ Research grants- innovative findings that influence patient experience outcomes</li> </ul>	<a href="http://www.theberylinstitute.org/">http://www.theberylinstitute.org/</a>
The Change Foundation	Partners Advancing Transitions in Health Care (or PATH): <ul style="list-style-type: none"> <li>■ Focus on Transitions &amp; on issues of integration, quality improvement and patient experience.                             <ul style="list-style-type: none"> <li>● Project Northumberland</li> </ul> </li> </ul>	<a href="http://www.change-foundation.ca/projects/path/">http://www.change-foundation.ca/projects/path/</a>

WEBSITE NAME	CONTENTS	LINK
The Council on Quality and Leadership	Resource & tool library on following topics: <ul style="list-style-type: none"> <li>■ Best Practices</li> <li>■ Community</li> <li>■ Leadership</li> <li>■ Person Centered</li> <li>■ Quality: Define, Measure, Improve</li> <li>■ Social Capital &amp; Relationships</li> </ul>	<a href="http://www.the-council.org/">http://www.the-council.org/</a>
The Health Foundation	Person-Centred Care Resource Centre: <ul style="list-style-type: none"> <li>■ Measuring the Patient Experience</li> <li>■ Videos on aspects of person-centred care e.g., shared decision making</li> </ul>	<a href="http://www.health.org.uk/areas-of-work/topics/person-centred-care/">http://www.health.org.uk/areas-of-work/topics/person-centred-care/</a> <a href="http://www.health.org.uk/publications/measuring-patient-experience/">http://www.health.org.uk/publications/measuring-patient-experience/</a>





WEBSITE NAME	CONTENTS	LINK
Victorian Government Health Information	<p>Person-Centred Practice:</p> <p><i>Resources and Tools:</i></p> <ul style="list-style-type: none"> <li>■ Advancing practice of patient- and family-centred care: How to get started</li> <li>■ Essence of care: Patient-focused benchmarks for clinical governance</li> <li>■ Improving the environment for older people in health services: An audit tool</li> <li>■ Patient- and family-centred care: A hospital self-assessment inventory</li> <li>■ Person-centred practice: Guide to implementing person-centred practice in your health service</li> <li>■ Sharing Package developed by WDHS.</li> </ul> <p><i>Benchmarking:</i></p> <ul style="list-style-type: none"> <li>■ Person-centred care statewide survey &amp; Instructions for use</li> </ul> <p><i>Further Reading:</i></p> <ul style="list-style-type: none"> <li>■ Guidelines: RNAO Nursing best practice guideline: Client Centred Care</li> <li>■ Human rights and responsibilities charter: Protection of freedoms and rights for everyone in Victoria</li> <li>■ Patient rehabilitation charter for in-patients</li> <li>■ Patient rehabilitation charter for in-patients: Staff accompaniments</li> </ul> <p><i>Discharge tip sheet: Remembering caregivers</i></p>	<a href="http://www.health.vic.gov.au/older/toolkit/02PersonCentredPractice/">http://www.health.vic.gov.au/older/toolkit/02PersonCentredPractice/</a>

## Appendix F: Common Themes in Patients' Charters of Rights

Various jurisdictions across the world have adopted charters of rights for patients as part of the increasing focus on person- and family-centred care. These charters outline what individuals who access the health system and its services can expect from the system and from health-care providers. These charters also outline patients' responsibilities related to accessing care.

Themes commonly found in patient charters include:

- The right to be treated with respect and dignity;
- The right to confidentiality and privacy in respect of their health information;
- The right to make informed decisions about their care and treatment options;
- The right to have all of their circumstances taken into account in care and wellness planning;
- The right to effective communication in order to facilitate their understanding of care and treatment options;
- The right to access information in a timely and reasonable manner; and
- The right to voice their concerns and to receive a timely response

(Horne, 2010)

In addition to the rights outlined above, a number of patient responsibilities are commonly found in charters. Patients are commonly expected to:

- Respect the rights of other patients and of health-care providers;
- Ensure they understand the information provided by health-care providers (e.g., by asking questions, following instructions, and understanding and following their care plan);
- Use health-care services appropriately and wisely;
- Learn how to access health-care services and use them appropriately; and
- Make healthy choices, where possible

(Horne, 2010)

Reference: Horne, F. (2010). *Putting people first: Part two—A summary of Albertans' views*. Retrieved from <http://www.health.alberta.ca/documents/Alberta-Health-Act-Summary-2010.pdf>

## Appendix G: Description of the Toolkit

Best practice guidelines can only be successfully implemented if planning, resources, organizational, and administrative supports are adequate and there is appropriate facilitation. To encourage successful implementation, an RNAO expert panel of nurses, researchers, and administrators has developed the *Toolkit: Implementation of Best Practice Guidelines* (2012d). The *Toolkit* is based on available evidence, theoretical perspectives, and consensus. We recommend the *Toolkit* for guiding the implementation of any clinical practice guideline in a health-care organization.

The *Toolkit* provides step-by-step directions for the individuals and groups involved in planning, coordinating, and facilitating the guideline implementation. These steps reflect a process that is dynamic and iterative rather than linear. Therefore, at each phase, preparation for the next phases and reflection on the previous phase is essential. Specifically, the *Toolkit* addresses the following key steps, as illustrated in the “Knowledge-to-Action” framework (Straus et al., 2009):

1. Identify the problem: Identify, review, and select knowledge (best practice guideline).
2. Adapt knowledge to the local context:
  - Assess barriers and facilitators to knowledge use, and
  - Identify resources.
3. Select, tailor, and implement interventions.
4. Monitor knowledge use.
5. Evaluate outcomes.
6. Sustain knowledge use.

Implementing guidelines to effect successful practice changes and positive clinical impact is a complex undertaking. The *Toolkit* is one key resource for managing this process. It can be downloaded at <http://RNAO.ca/bpg/resources/toolkit-implementation-best-practice-guidelines-second-edition>

# Endorsements



## ACCREDITATION AGRÉMENT CANADA

Better Quality. Better Health.  
Meilleure qualité. Meilleure santé.

April 1, 2015

Ms. Doris Grinspun RN, MSN, PhD, LLD(hon), O.ONT.  
Chief Executive Officer  
Registered Nurse' Association of Ontario (RNAO)  
158 Pearl Street  
Toronto, ON  
M5H 1L3

Dear Doris,

**Re: BPG Person- and Family-Centred Care**

On behalf of Accreditation Canada, I am delighted to convey endorsement from Accreditation Canada for RNAO's evidence-based clinical Best Practice Guideline on *Person- and Family-Centred Care*. Under your leadership, RNAO continues to make amazing progress in the area of Best Practice Guidelines – well done!

As you know, the Accreditation Canada *Qmentum* program is designed to improve health care quality and safety, while also improving client outcomes and experience through a client and family-centred approach. Accreditation Canada recently strengthened the client and family-centred focus and content of the standards of excellence, to further support meaningful partnership with clients and families in all aspects of service design, delivery, and evaluation. Further information about this important enhancement can be provided to you upon request. We are pleased to see that the revised RNAO *Person- and Family-Centred Care* guidelines align well with our new requirements.

We want to congratulate you on delivering another robust evidence-based guideline. RNAO's rigorous process has resulted in a set of evidence-based recommendations related to nursing and inter-professional practice for a broad range of organizations. The RNAO guidelines will support health care providers and organizations to strengthen the person- and family-centred approach to their services. Further, this guideline will assist health care organizations to build a person- and family-centred culture by fostering equal partnerships with persons and their families, leading to enhanced quality, outcomes, and the experience of health care for all those served by the Canadian health care system.

Congratulations on this important work!

Sincerely,

Wendy Nicklin  
President and Chief Executive Officer

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[accreditation.ca](http://accreditation.ca)



April 7, 2015

Doris Grinspun RN, MSN, PhD, LLD(hon), O.ONT.  
 Chief Executive Officer  
 Registered Nurse' Association of Ontario (RNAO)  
 158 Pearl Street  
 Toronto, ON  
 M5H 1L3

Dear Dr. Grinspun,

The Canadian Association for People-Centred Health (CAPCH) believes in a person-centred health system. This guideline is supportive of the CAPCH vision of acknowledging each person as the nucleus in their health and wellness journey. By assisting the person to become more knowledgeable about their health through education and the sharing of information, each person has the option to better manage their care, select their partners in care and be responsible for their health and wellness.

CAPCH is pleased to endorse RNAO's timely Clinical Best Practice Guideline – *Person- and Family-Centred Care*. With its robust evidence-based focus on enhancing person-and family-centred care, this guideline will greatly strengthen the use of best practices associated with enhancing the partnership between health-care providers, the person and their family.

The recommendations in the guidelines are another step in addressing the evidence-based best practices associated with person- and family-centred care at the individual, practitioner, organization, and health system level and will promote the person as the central partner in their health care by enhancing their health literacy and collaboration with health-care providers. This ultimately will improve the efficiency and quality of care while lessening the demands on the healthcare system.

CAPCH is committed to establishing standards for people/person-centred health care and we believe RNAO's *Person- and Family-Centred Care* guideline will assist us with promoting a people-centred health-care culture.

Best regards,

Dr. Vaughan Glover  
 CEO  
 CAPCH

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P.O. Box 309, Arnprior, Ontario K7S 3H6 • telephone (613) 623-9500 • fax (613) 623-9800  
[www.peoplecentredhealth.ca](http://www.peoplecentredhealth.ca)

CANADIAN  
NURSES  
ASSOCIATION



ASSOCIATION DES  
INFIRMIÈRES ET  
INFIRMIERS DU CANADA

March 31, 2015

Doris Grinspun, RN, MSN, PhD, LLD(hon), O.ONT  
Chief Executive Officer  
Registered Nurses' Association of Ontario  
158 Pearl Street  
Toronto, ON M5H 1L3

VIA EMAIL (Hard copy to follow): [dgrinspun@rno.org](mailto:dgrinspun@rno.org)

Dear Dr. Grinspun,

On behalf of the Canadian Nurses Association (CNA), I am pleased to endorse RNO's clinical best practice guideline (BPG): *Person- and Family-Centred Care*. Funded by the Ontario Ministry of Health and Long-Term Care, this updated guideline, which replaces *Client Centred Care* (2002) and its supplement (2006), will strengthen the partnership between nurses and the persons and families they care for across the continuum of care.

CNA is a federation of 11 provincial and territorial registered nursing associations and colleges representing over 135,000 registered nurses and nurse practitioners. It advances the practice and profession of nursing to improve health outcomes and strengthen Canada's publicly funded, not-for-profit health system, by providing national and international leadership in nursing and health.

We therefore appreciate how integral evidence-informed decision-making is for achieving quality care in all domains of nursing practice and more generally, for making positive changes across the health-care system. By addressing evidence-informed best practices associated with the individual nurse, the employer, and the health system, RNO's latest BPG is sure to enhance clinical outcomes and overall satisfaction with health-care delivery.

CNA is committed to advancing nursing excellence and positive health outcomes in the interest of the public. In keeping with that mission, we believe *Person-and Family-Centred Care* will be an important resource for nurses.

With warmest regards,

Anne Sutherland Boal, RN, BA, MHSA  
Chief Executive Officer



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March 26, 2015

Doris Grinspun RN, MSN, PhD, LLD(hon), O.ONT.  
Chief Executive Officer  
Registered Nurse<sup>1</sup> Association of Ontario (RNAO)  
158 Pearl Street  
Toronto, ON  
M5H 1L3

Dear Dr. Grinspun,

The Canadian Patient Safety Institute (CPSI) exists to intensify awareness and assist others to implement ideas and best practices to support health-system transformation. CPSI is pleased to endorse RNAO's timely Clinical Best Practice Guideline – *Person- and Family-Centred Care*. With its robust evidence-based focus on enhancing person-and family-centred care, this guideline will greatly strengthen the use of best practices associated with enhancing the partnership between health-care providers and the person (and their family) by supporting the personalization of care to meet the individual needs of the person thereby optimizing their clinical outcomes and overall satisfaction with the delivery of health-system services.

This guideline is directly related to our mandate of inspiring extraordinary improvement in patient safety and quality of health care and services. The recommendations address the evidence-based best practices associated with person- and family-centred care at the individual practitioner, organization, and health system level and will enable our organization to work with other health-care settings towards creating a strong person-and family-centred culture within the health system.

CPSI is committed to having the safest health-care system through the use of evidence-based practices, and we believe RNAO's *Person- and Family-Centred Care* guideline will greatly support our work to move the health system forward to achieve optimal safety and quality in the delivery of health care and services.

Congratulations and many thanks,

Chris Power, BScN MHSA  
Chief Executive Officer  
CPSI

*Building a safer health system*  
*Accroître la sécurité du système de santé*

[www.patientsafetyinstitute.ca](http://www.patientsafetyinstitute.ca)  
[www.securitedespatients.ca](http://www.securitedespatients.ca)

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Thursday April 2, 2015

Dr. Doris Grinspun, RN, MSN, PhD, LLD(hon), O.ONT.  
Chief Executive Officer  
Registered Nurses' Association of Ontario (RNAO) Thursday  
158 Pearl Street  
Toronto, Ontario  
M5H 1L3

Dear Dr. Grinspun,

A handwritten signature in black ink that reads "DORIS".

As the provincial advisor on the quality of health care, Health Quality Ontario (HQP) is pleased to endorse the RNAO's Clinical Best Practice Guideline – *Person- and Family-Centred Care*. With its robust evidence-based focus on enhancing person-centred care, this guideline will strengthen the use of best practices, and will enhance the partnership between nurses, other health-care providers and persons and families receiving care. By supporting the personalization of care to meet individual needs, we believe the guideline will help to both optimize clinical outcomes and overall satisfaction with the delivery of health-system services.

As an organization that promotes quality improvement at all levels of the health system, we appreciate that the guideline provides evidence-based recommendations for care at the individual practitioner, organization, and health system levels. This guidance will enable HQO to work with other health-care organizations towards creating a strong person-and family-centred culture across the health system.

This work is directly related to HQO's mission of transforming Ontario's health system in order to deliver a better experience of care and better outcomes for Ontarians. We are confident that RNAO's *Person- and Family-Centred Care* guideline is an important contribution that will help to improve the quality and experience of care across our province.

Best regards,

A handwritten signature in black ink, appearing to be "Joshua Tepper".

Dr. Joshua Tepper, MD, MPH, MBA  
President and Chief Executive Officer

ENDORSEMENTS



April 6<sup>th</sup>, 2015

Doris Grinspun RN, MSN, PhD, LLD(hon), O.ONT.  
Chief Executive Officer  
Registered Nurse' Association of Ontario (RNAO)  
158 Pearl Street  
Toronto, ON  
M5H 1L3

Dear Doris,

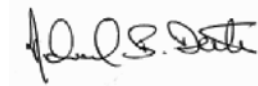
Patients Canada is a patient-led organization that aims to increase the voice of the patient and their families in Canada's health-care system. Patients Canada believes patients and caregivers must be active participants in the transformation of Canada's health system.

Patients Canada was pleased to participate in the development of the RNAO's timely Clinical Best Practice Guideline – *Person- and Family-Centred Care*. As such we are also pleased to endorse it. With its robust evidence-based focus on enhancing person-and family-centred care, this guideline will greatly strengthen the use of best practices associated with enhancing the partnership between health-care providers and the person (and their family) by supporting the personalization of care to meet the individual needs of the person thereby optimizing their clinical outcomes and overall satisfaction with the delivery of health-system services.

This guideline is directly related to our vision of bringing the patient's perspective into healthcare. The recommendations address the evidence-based best practices associated with person- and family-centred care at the individual practitioner, organization, and health system level and will promote the patient's voice and perspective as the key perspective to creating a strong person-and family-centred culture within our health system.

Patients Canada is committed to increasing the voice of the patient and their families in Canada's health-care system health-care system and we believe RNAO's *Person- and Family-Centred Care* guideline will help patients and families move the health system forward to improve satisfaction and the quality of care experienced by Canadians who our health care and services.

Congratulations and thanks for the excellent work!



---

Michael Decter  
Chair of the Board  
Patients Canada

**ia** BPG

INTERNATIONAL  
AFFAIRS & BEST PRACTICE  
GUIDELINES

TRANSFORMING  
NURSING THROUGH  
KNOWLEDGE

# Clinical Best Practice Guidelines

MAY 2015

# Person- and Family-Centred Care



Registered Nurses' Association of Ontario  
L'Association des infirmières et infirmiers  
autorisés de l'Ontario

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